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ABSTRACT

This document consists of the third section of a book written to educate and inform those in the helping professions on how to deal with Acquired Immune Deficiency Syndrome (AIDS). The four chapters in section 3 examine special issues for people with AIDS. "Caring for People With AIDS Dementia Complex" (Alicia Boccellari, Craig Kain, and Michael Shore) describes the clinical aspects of the AIDS dementia complex produced by the human immunodeficiency virus' (HIV) insidious ability to cross the blood-brain barrier. "Treating AIDS: A Family Therapy Perspective" (John Curtis) describes the impact of AIDS on the family system, defining family in its broadest sense and offering counselors suggestions on working with the "second chance" family as well as the nuclear family of someone with AIDS, his or her friends and lovers, as well as his or her spouse. "Modern Hospice Care" (Sr. Patrice Murphy and Carole Donovan) describes hospice care as one option that those in the last stages of life have. It also examines the bereavement services provided by hospice caregivers to loved ones that complete the continuum of hospice care. "Sustaining the Spirit" (Rev. Albert Ogle) shares a perspective on the deepest and most personal struggle that an HIV-infected person can face. It includes moving work by members of one parish, successfully struggling to counter the debilitating feelings of powerlessness AIDS encourages. (NB)

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Section Three

The Physical, Psychological, and Spiritual Assault

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Section Introduction

Daily life for people with AIDS (PWAs) involves the constant assault to their physical, psychological, and spiritual being. PWAs live in a world where, as one client stated, "committing suicide is redundant." For counselors to work effectively with people with AIDS, they must understand and be able to empathize with the special issues that PWAs face. This section describes some of those issues.

One of the first things that a person with AIDS must confront is a weakening physical condition. As the AIDS crisis continues, it becomes more common for physicians and counselors to observe psychoneurological complications as a result of HIV infection. In fact, neurological symptomatology may be the first clue to HIV infection in a high-risk person. In chapter 8, Boccellari, Kain, and Shore describe the clinical aspects the AIDS dementia complex produced by the HIV's insidious ability to cross the blood-brain barrier.

Counselors who adhere to a systems orientation know that a crisis involving one member of a system quickly affects all other members. This is particularly true of the crises, large and small, brought on by AIDS. In chapter 9, Curtis describes the impact of AIDS on the family system. Curtis defines family in its broadest sense, allowing him to offer counselors suggestions on working with the "second chance" family as well as the nuclear family of someone with AIDS, the PWA's friends and lovers, as well as his or her husband or wife.

One of the decisions that people with AIDS must make is how to spend the last days of their lives. In chapter 10, Murphy and Donovan describe one option that those in the last stages of life continue to desire: hospice care. They believe that because hospice care is managed by an interdisciplinary team, it offers many opportunities for counselors to become involved.

The chapter also examines the bereavement services provided by hospice caregivers to loved ones that complete the continuum of hospice care.

Although AIDS can be seen as a disease that attacks the body, those who have worked with people with AIDS experience it as a "dis-ease" that also attacks the soul. In chapter 11, on spiritual issues, Ogle eloquently shares a perspective on the deepest and most personal struggle that an HIV-infected person can face. Ogle writes that articulating experiences of "exile" and "calling" are important if spiritual people are somehow to make sense of their lives and losses in this time of AIDS. This chapter includes moving work by members of one parish, successfully struggling to counter the tremendously debilitating feelings of powerlessness AIDS encourages.

The wide scope of this third section of *No Longer Immune: A Counselor's Guide to AIDS* reflects the complexity of the AIDS crisis. Counselors working with people with AIDS, their families, and loved ones must be prepared to expand the scope of the work that they do, facing intense, exhausting, and rewarding challenges. As the chapters in this section suggest, AIDS is more than a disease of the body—it is one of the mind, heart, and soul as well.

Chapter 8

CARING FOR PEOPLE WITH AIDS DEMENTIA COMPLEX

Alicia Boccellari, Craig D. Kain, and Michael D. Shore

An aspect of the AIDS crisis of growing importance to counselors is the ability of the AIDS virus to cross the blood-brain barrier, producing an associated dementia. Counselors find it difficult enough to watch what should be young, attractive, successful clients physically waste away with skin lesions, pneumonia, and other opportunistic infections. Much harder is the struggle of watching these same clients lose their mental functioning, their ability to walk, talk, and comprehend, their ability to feed themselves, to wash themselves, and to maintain their independence. Yet, this is the case with many individuals diagnosed with AIDS dementia complex (ADC).

It is currently estimated that 90% of AIDS patients have evidence of the AIDS virus in their brain at the time of their death (Navia, Jordan, & Price, 1986); as many as 25% of people may present with neurological changes before the development of opportunistic infections (Navia & Price, 1987). In August of 1987, in recognition of the extreme frequency with which the AIDS dementia complex (ADC) is clinically observed, the Centers for Disease Control (CDC) changed the inclusion criterion for individuals who would receive an AIDS diagnosis. Until then, presence of an opportunistic infection like pneumocystis or Kaposi's sarcoma was required. As changed, the current criteria now include ADC as a disorder that warrants an AIDS diagnosis. The diagnostic criteria of the CDC include a positive antibody test for HIV; a negative lumbar puncture, and either a negative CT (computer tomography) scan or MRI (Magnetic Resonance Imaging), *or* findings consistent with atrophy. Ad-

ditional criteria include "clinical findings of disabling cognitive and/or motor dysfunction interfering with occupation or activities of daily living . . . in the absence of concurrent illness or conditions other than HIV infection that could explain the findings" (CDC, 1987).

Little has been written specifically about caring for the patient with ADC. Although there are some similarities between this issue and caring for patients with Alzheimer's and other dementias, the patient with AIDS is quite different. This chapter examines the complexities of working with clients with ADC. First though, an overview will be presented.

Overview of the AIDS Dementia Complex

AIDS dementia complex tends to start subtly, and progresses in a slow insidious fashion. Early manifestations cluster around a triad of cognitive, behavioral, and motor symptoms (Navia, Jordan, & Price, 1986). Cognitive symptoms are reflected in the patient's presenting complaints of difficulty paying attention, memory problems, and mental slowing. Patients often report that they cannot think as quickly as usual. Behavioral changes include symptoms such as apathy, withdrawal, depression, loss of spontaneity, and occasionally irritability and emotional lability. One uncertainty with this initial stage is that many of the symptoms described may be symptoms of depression and not specifically those of an alteration in brain function. One of the immediate differential diagnoses that counselors need to make is whether the person exhibits the memory and concentration problems of someone with either a reactive or major depression, or ADC. Of course, both depression and ADC can coexist. Also important to note is that occasionally, some people develop an organic psychosis (Boccellari, Dilley, & Shore, 1988); although this may happen in the early stages of ADC, it tends to occur later in the disease process. Early motor symptoms include complaints of bilateral leg weakness, balance problems, and loss of fine motor control. Occasionally the patient develops a hand tremor. Patients may notice a change in the handwriting, with writing slowness and a sense of arduousness in completing tasks.

In the late stages of ADC people become globally demented. They develop impairment in virtually all areas: mem-

ory, language-based abilities, and visual-spatial abilities. Often people deteriorate to the point where they lose the ability to care for themselves and are unable to perform routine overlearned tasks such as dressing, bathing, or feeding themselves. Frequently the behavioral changes will include a growing passivity with muteness and a general unresponsiveness to the environment. Personality changes at this stage can be quite dramatic as well. The patient may forget and become confused and not recognize even familiar people. There may also be behavioral change in the form of agitation, restlessness, or disinhibition. Late stage motor changes include general slowing on motor tasks, ataxia, and increased weakness, particularly in the legs. Mobility problems may be so extreme that patients may be bedridden at this point.

Not much is really known about how rapidly people progress from early stage to late stage ADC. Individual differences are great, with some people reaching the end stage of the dementia in as quickly as 3 to 4 months (Navia, Jordan, & Price, 1986), with other people tending to progress at a slower rate. Several cofactors have been suggested. For example, IV drug users seem to progress more rapidly with the dementia than do nonusers. It may be that the IV drug users begin with compromised abilities as a product of long-term substance abuse, and are therefore unable to adapt or compensate as they develop HIV-related difficulties. People with a past history of neurological illness, head trauma, or stroke may also deteriorate at a faster rate. Individuals who are quite physically ill with AIDS, for example individuals who have had three or four bouts with pneumocystis, who are quite frail and fatigued in general, are going to deteriorate functionally more quickly too; they are not going to have the endurance or ability to compensate for their problems.

The Neuropsychology Service at San Francisco General Hospital is finding that in early stages of AIDS dementia, people's immediate concentration and attention abilities are relatively intact or suggest only mild abnormalities (Dilley & Boccellari, 1988). If neuropsychological evaluators use the traditional mental status task of asking clients to remember three words and then ask for recall 5 minutes later, clients may be well able to do this task without difficulty. However, if a delayed memory task is administered to the same patient, it is likely that poor performance will be seen. A majority of ADC patients show

specific difficulty with 30-minute delay memory testing even when their immediate memory performance is intact.

Neurological examinations often reveal gait disturbance, ataxia, leg weakness, and hyper-reflexia that may be evident more in the legs than in the upper extremities (Navia, Jordan, & Price, 1986). In early stages computer tomography (CT) scans often look unremarkable, although occasionally they will show cortical atrophy and ventricular enlargement. MRIs (Magnetic Resonance Imaging technique) seem to be superior to the CT scan in identifying AIDS dementia apparently because of the MRI's sensitivity in visualizing white matter changes in the brain.

How does ADC differ from the well-known Alzheimer's dementia? Specifically, when Navia and his colleagues began looking at the brains of people who died from AIDS (excluding from the series people with known focal infections like toxoplasmosis and CNS lymphoma) 90% of these people did show evidence on brain pathology of the AIDS virus infiltration (Navia, Cho, Petito, & Price, 1986). The identified abnormalities were found predominantly in the white matter and in subcortical structures of the brain, particularly the basal ganglia and the thalamus, with relative sparing of the cortical mantle. These results led them to conclude that the AIDS dementia might best be characterized as a subcortical dementia. There seems to be an affinity of the virus for glial cells, the cells in the brain that provide nurturance and support to the neurons. In contrast, Alzheimer's dementia seems to assault primarily the cortical mantle and is thus identified as a cortical dementia.

Subcortical dementia was first alluded to in 1912 by Wilson as he was describing the disorder that now bears his name, Wilson's disease. In commenting on a series of patients with Wilson's disease, he noted the presence of "psychical symptoms" (Cummings, 1986). He described a propensity for the development of two constellations of personality changes in patients with this illness. One type was the appearance of depression and apathy. The second was that of a more organic psychosis as manifested by hyperactivity and grandiosity, either resembling a manic type of psychosis, or in some cases resembling a schizophreniform psychosis. He also noted that when compared to people with senile dementia or what is currently known as Alzheimer's disease, the person with Wilson's disease did not seem to have the same language-based problems, language comprehension problems, or naming problems. Patients with Wilson's disease developed many different motor problems whereas

the Alzheimer's patient tended not to do so, at least not in the early stages. These differences are important for it would seem that ADC is a subcortical dementia. Given the higher incidence of depression and other personality changes seen in subcortical dementia (including Huntington's chorea and Parkinson's), it is not surprising to find such problems appearing with the ADC patient.

To provide counselors with an expanded clinical picture of ADC, two clinical case vignettes are presented.

Case one: Tom, a 40-year-old White gay man with a master's degree in architecture, was at the time of evaluation working as an architect. He had no previous psychiatric history, no significant history of substance or alcohol abuse, and at the time of evaluation, had had an ARC diagnosis for about 6 months. He was brought into the emergency room by his lover who reported that he had been having increasing memory problems for about 3 months and that he had also developed a bilateral hand tremor and more recently an unsteady gait. He was also reported to be in danger of losing his job because of poor work performance. Work problems were striking in light of the fact that Tom had worked for the same company for over 10 years and had advanced to a high level of responsibility. He was admitted to the neurology service where a neurologic exam proved to be within normal limits except for mild impairment on a finger-to-nose task, and a mildly ataxic gait. A C.T. scan revealed diffuse atrophy with multiple areas of hypodensity of the white matter felt to be consistent with ADC. Tom was referred to the Neuropsychology Service and administered a battery of neuropsychological tests, which measured a full range of motor, memory, visual-spatial, and abstract reasoning abilities. On a Bender-Gestalt Test (which asks a person to copy basic designs from a sample on a card), Tom distorted the designs by fragmenting them to such a degree that many designs were unrecognizable to the examiner. When asked if the designs looked like the original, the patient replied that they did. Tom suffered from anosognosia, not fully realizing the extent or nature of his problems. Such a condition is common with people with ADC.

who, early on, complain about some of their problems but as they worsen, they complain less, becoming oblivious. Given Tom's background in architecture, he should have been able to execute these designs flawlessly.

Tom is a generally representative case of ADC. Results from his CT scan were consistent with the ADC diagnosis as well as the presenting signs of motor disturbance. The following vignette presents a different kind of case.

Case Two: Dan, a 35-year-old gay White male accountant with an ARC diagnosis of 1 year was continuing to work at the time he was evaluated. Approximately 2 months prior to being hospitalized, he began having memory problems. His lover noted that he progressively began to spend large sums of money that they did not have. He also began to demonstrate intense behavioral outbursts and was admitted to the hospital after threatening to hurt himself following a minor dispute with his lover. On admission he was described as irritable, emotionally labile, hyperactive, restless, with grandiose thinking, flight of ideas, and tangentiality. He was also noted to have poor insight into his problems. Dan demonstrated a delusional belief that he had found a cure for AIDS, had cured himself of AIDS, and was going to cure other people of AIDS. The results of a lumbar puncture conducted at the hospital revealed slightly increased protein, which is sometimes found in people with AIDS dementia. A CT scan was done and found to be within normal limits. However, an MRI revealed multiple small abnormalities in the white matter of the brain that was consistent with AIDS dementia. Dan was started on a very small dose (2 mg.) of Haldol for treatment of the agitation and the hyperactivity. He quickly developed fairly severe extrapyramidal symptoms, which necessitated discontinuing this medication. This drug sensitivity is reasonably related to the specific subcortical attack brought on by the virus particularly to the basal ganglia area, which probably compounded the action of the Haldol resulting in a lowered threshold for the development of extrapyramidal symptoms.

On referral to the Neuropsychology Service, Dan was administered an IQ test. Past records showed that at one point he had an IQ of 155 (in the top 1% of the population in terms of intellectual functioning). At the time of his hospital evaluation Dan's IQ was 85. One of the other tests administered was the Wechsler Memory Scale. On one part of this test he was shown a drawing for 10 seconds. It was taken away and he was asked to sketch the drawing from memory. The drawing produced was quite perseverative. His immediate memory was quite impaired. When asked 30 minutes later to draw the design he had initially seen, he did not remember sketching it in the first place, denied that he had drawn anything, and so was unable to produce anything at all.

These 2 cases demonstrate the common pattern of deficits that occur in ADC patients: difficulty on memory tasks, particularly on 30-minute delay, visual-abstract reasoning difficulties, motor slowing, cognitive slowing, and difficulty with mental flexibility. In addition, Case 2 represents an organic-mania variant of ADC. It also highlights the importance of considering an organic psychosis in HIV-infected individuals who are presenting with psychiatric symptoms.

Counseling Interventions

The type of intervention a counselor can employ clearly depends on where a particular client is in the course of ADC. Generally, two stages need to be differentiated. The first marks the early to midstage ADC, whereas the second encompasses mid- to late-stage AIDS dementia. During stage one, individuals can actively participate in their own treatment and management and should be encouraged to do so. During the second stage, the individual's ability to participate in his or her own care is compromised. At this point the counselor or other caregiver needs to step in and take on more responsibility for caring for the individual with ADC, making the decisions and plans that are necessary.

As a bit of background, there are generally three approaches, or theories, regarding the care of the individual with brain dysfunction. The first is a theory of "Restitution of Lost

Functions" that leads to the attempt to bring back lost abilities, restoring what can be restored. Although this theory is often used with people with static dysfunction, for example an individual with head trauma, there is little place for it in working with people with ADC. With individuals with a progressively demential illness, like ADC, where the HIV virus is continuing to attack and destroy brain tissue, it is highly unlikely that a counselor could help a client recover lost abilities.

The second model or theory is that of "Adaptation and Compensation." This second approach is more realistic and is used best during the early to middle stages of ADC. The thrust of this approach is essentially to encourage and reinforce the strengths the individual has left. The goal of this approach is to fully include the patient in decision making. This helps to support and reinforce the individual's self-esteem.

The third model, "Environmental Engineering," focuses on structuring the patient's environment to make it less frightening, less confusing, and more understandable. This approach is best used in the middle to end stages of ADC.

Much of the discussion that follows is, in fact, a common-sense, practical approach. Working with the individual with ADC can at times feel overwhelming. It is therefore important not to lose sight of the basic strength of common sense, a good heart, and hard work.

Stage I—Early to Midstage ADC Intervention: The Adaptation and Compensation Model

The preferred intervention for those in early to midstage ADC is the utilization of the Adaptation and Compensation model. One goal of this stage is education, involving both the patient and his or her family members and friends and lovers, on the physical, cognitive, and behavioral changes that occur with the AIDS dementia complex. Caregivers specifically need to be informed of the behavioral changes that will take place. Many caregivers respond to behavioral problems as if the infected person had some control over them, as if the person is acting deliberately, as if there were a volitional component to the behaviors. Counselors will often hear family members tell the person to "just stop it" when, in fact, the patient cannot control some of these behaviors. For example, the distractibility that is often seen in people with ADC may be attributed by the

caregiver to anxiety or disinterest or simply the patient's not paying attention. The patient who may seem stubborn in the face of ordinary requests may be actually demonstrating the mental inflexibility seen in this dementia. The patient who seems easily upset or labile or who is difficult to be around may be exhibiting the behavioral changes and loss of impulse control commonly seen in people with ADC. It therefore becomes essential that people caring for the ADC patient recognize that many of these behaviors are not deliberate and that the patient may have little ability to control them. Of course, one of the counselor's tasks is to help the caregivers distinguish between those behaviors the patient does have control over versus those behaviors over which the patient does not have control.

Educating family members and friends can be a difficult task because so much is as yet unknown about this disorder. Although counselors can inform people about certain aspects of ADC, such as what some of the symptoms may be and a little bit of what to expect, it is difficult to answer questions about the course of the illness and how rapidly it progresses because the exact course of ADC has not yet been well defined. In fact, it would seem to have a variable course from person to person. It is important, therefore, in communicating with caregivers, for counselors to respond as honestly as possible and to strike a balance between useful knowledge and the considerable uncertainty that exists.

The education of the person with ADC is often best accomplished within the context of supportive psychotherapy or counseling. This means that counselors need to shift from the traditional nondirective role as therapist to an active role that relies heavily on direct interaction with the patient and the caregiver. Eventually, the counselor may need to function more as a case manager, or as a liaison to other medical professionals, financial advisors, and attorneys.

In addition to individual therapy, it is often extremely helpful to provide couples therapy or group therapy to the patient with ADC and his or her caregivers (family members, lovers, and friends). Group therapy offers the caregivers involved with the ADC patient an opportunity to begin to discuss the role changes that are occurring in the family system or unit. Often the roles change so drastically that a person who was previously the breadwinner, or the person who did most of the cooking or cleaning or paid the bills, is no longer able to do so. With these changes, many times the patient may begin to feel a sense

of anger, resentment, and guilt about no longer being able to perform certain tasks. The caregivers may also be feeling some resentment that the person is no longer able to perform his or her previous duties. Caregivers may also feel a sense of despair. These are feelings that people often do not talk about and, when unventilated, can destroy the substance of the relationship. Couples therapy or a group format helps to facilitate the exchange of these types of feelings and information and helps both the patient and caregiver come to a better understanding of how to cope with such changes.

Counselors must also recognize that there are two extreme reactions to the ADC patient that may develop. One extreme is that of denial, whereby both the patient and the caregivers may downplay the seriousness of the emerging symptoms. The patient may be doing this as part of the use of psychological denial or as part of an organic denial where the patient is mentally unable to monitor his or her behavior. Family members may experience intense discomfort in observing the patient's dementia and find it necessary to downplay the severity of the situation. Counselors will hear comments like, "well, he's always been like that; this is nothing new." Typically this stage of denial does not last long, particularly as the dementia progresses and it becomes more difficult for the caregivers to hold onto the stance of denial.

The other extreme may be the tendency for the caregiver to act as if the patient with ADC can no longer do anything independently or successfully. There may be a tendency to take over and take complete charge of what the patient is doing in his or her life. This inevitably leads to problems. One of the main issues that people with terminal illnesses experience is a feeling that they no longer have any control over their life, that they no longer have any power to influence their circumstances. When someone with a terminal illness also develops dementia, this issue becomes compounded by real losses and often the patient feels a sense of complete uselessness and a sense that there is nothing at all he or she can do right. At this stage, it is important that counselors talk to caregivers to identify those activities the patient can still do and responsibilities that can be maintained. This may be facilitated by setting up daily and short-term goals that are realistic and achievable for the patient, and by including the patient in larger decision-making processes at this early stage. The individual should be encouraged to stay active and involved.

In the early to midstage ADC, compensation for cognitive problems can be enhanced through encouraging the individual to keep track of needs and events by writing them down. Often patients will report that they went to see their physician and were given information about their medical status, but by the time they got home they could not remember anything that was discussed. In the course of therapy, it is not uncommon for the patient to be seemingly attentive during the course of a discussion only to telephone the therapist later on during the week saying "I don't remember what we talked about." It may be more helpful in these particular circumstances to bring and use a tape recorder. Thus, when the patient has a need to review conversations, this can be easily done.

It is also important to keep in mind that people with ADC lose cognitive efficiency, so mistakes are common, particularly when going too fast. It is important to give people permission to take their time. Counselors can give this permission directly, and also point out that not everything needs to be done at once. This helps to decrease mistakes that often arise through an impulsive problem-solving style.

At this early stage counselors can reinforce and stimulate general mental activity. Clients can be encouraged to play games like scrabble, card games, or checkers. In moderation these activities are not stressful as much as enjoyable. Such activities are helpful because they reinforce and teach patients something about the manner with which the patient needs to go about paying attention to all activities. A balance needs to be struck, however, between games and activities that are stimulating, challenging, and enjoyable, versus things that are frustrating and mildly difficult.

To be dying from AIDS and to be told one is suffering from dementia is extremely frightening. Everyone has a different idea of what the term "dementia" means. Asking patients and their caregivers to discuss what this term means to each of them helps specifically to address their individual fears. Misconceptions or myths about dementia can then be dispelled and a clearer understanding achieved.

It is particularly important for patients with ADC to avoid fatigue. Fatigue seems to cause a worsening of cognitive problems. Mornings tend to be best, and as the day goes on patients tend to become tired and less able to stay on top of their circumstances. Patients can be encouraged to schedule important appointments at the beginning of the day. Counselors will also

want to give people permission to take rest periods during the day, even if it is only a half-hour nap in the afternoon. Counselors also can encourage exercise such as daily walks. Daily walks may help relieve tension and reduce stress and also help keep the patient involved in the world.

Counselors can assist the patient in avoiding stressful situations. For example, a patient with midstage dementia reported going to a government office with his lover to apply for food stamps. While in the overstimulating environment of the food stamp office, with the food stamp worker talking, filling out forms, and phones ringing, the patient found himself getting increasingly irritable and anxious and became confused. He ended up escalating by becoming extremely upset and labile. In talking later to this patient, the counselor was able to help the patient identify the stressful situations in his life. Some situations could still be managed, others required outside assistance. One of the accomplishments that resulted was the sharing of early signs of emotional escalation with the lover, who was then able to move quickly to help out when needed. The patient was told that when he found himself getting irritable, he should not keep it inside, but, rather, tell his lover about it. The lover could then take charge and encourage the patient to take a few minutes away from the situation to help regain composure. Counselors need to recognize that nobody can avoid all stressful situations, and that anticipation, planning, and having alternatives enable a higher level of functioning.

Stage II—Mid- to Late-Stage AIDS Dementia Complex Interventions: Environmental Engineering

As mentioned, AIDS dementia complex is a progressive demential illness. At this time there is no cure for ADC. In the early stages counselors and caregivers can continue to feel a sense of hope. Patients still interact with us, still actively participate in their own care, and still tell us what it is they need. During the mid- to late-stage ADC, life becomes not only a struggle to survive but also a struggle to maintain a sense of one's identity, a sense of who one is in relationship to other people in the world. As this sense of identity begins to erode, persons with ADC may get to the point where they are no longer able to fully appreciate their own needs and are consequently unable to care for themselves. In this second stage, collaboration

among counselors, physicians, caregivers, and nursing professionals is essential to successful management. Environmental engineering is often a useful approach for people with mid- to late-stage ADC. People with demential illnesses eventually lose their capacity to be mentally flexible and adapt to changes, resulting in their inability to deal with novel situations. Much of what people do on a day-to-day basis is deal with the complexities of an ever-changing world, and patients with late-stage ADC are incapable of doing this. They may not be able to monitor their own behavior or control their actions.

As patients are unable to change and control their own behavior, the environment has to change for them. Environmental engineering refers to structuring a patient's world to minimize the impact of lost abilities. The more structure that is provided by the environment, the easier it is for demential patients to understand and process the world around them. This is an approach dramatically different from those most people in the helping professions are used to. As therapists and counselors, we generally expect and encourage our patients to change. In this approach, however, health practitioners become instrumental in altering the patient's environment whereby less emphasis is placed on the patient changing. Realizing that the environment can be positively altered gives a new sense of hope, and patients' quality of life can be enhanced. Most counselors and therapists are aware of the importance of keeping people oriented, aware of the time, the date, and geographical location. Our anchors to reality also include knowing who we are, where we are, and a sense why we are there. It is important for the demential individual to be given orienting cues. For example, if the patient is at home or in the hospital, a calendar provides cues to the day, month, and year. Clocks are helpful in keeping people oriented to the time of day; many clients prefer digital clocks to avoid the confusing visual task of distinguishing between the minute and hour hands of a regular clock. In places like hospices or group living situations, current event groups for patients to keep them in touch with what is going on both in the treatment place as well as the rest of the world are helpful. The client's environment should be kept consistent with posted routine schedules. Sudden changes can often cause a worsening of confusion.

It is helpful to keep familiar objects around the patient, particularly if the patient is in the hospital. Caregivers can be encouraged to bring in photographs or personal objects to help

the patient feel less afraid. Speaking of familiar names, places, or interests that the patient has had in the past is particularly important. It is also important to keep in mind that for people with ADC, their remote memory may be largely intact. It is best to encourage people to talk about things that they are competent to talk about. When counselors need to quiz patients on what year it is, what time of day is it, and where they are living, it is advisable to follow this with questions that the patient can, in fact, answer. It is best that patients be given only one thing to do at a time. For example the lover of a person with ADC complained to a counselor that he could not get the person to take a bath. In studying this situation, it was realized that for someone who is demented, taking a bath is not the easiest thing because of the many different steps involved. It was not that the patient did not want to take a bath. Rather, he could not organize himself in sequence. Often when a patient refuses to do something, it is helpful to understand the problem by breaking the task down into pieces. Presenting the task one step at a time usually results in increased cooperation. Information should also be presented slowly and one step at a time. Counselors and caregivers should not assume that the person is following what is being said. It is sometimes helpful to have the person repeat back what was said. Although this does not necessarily ensure that the patient *understands* what is being said, it increases the likelihood that the patient at least hears you accurately. If the patient can still read, he or she can be encouraged to keep track of needs and events by writing them down in a diary or daily log.

Counselors and caregivers need to keep in mind that too much or too little stimulation can lead to confusion, agitation, and fearfulness. The patient's living space should be uncluttered. Although friends and family should be encouraged to visit the patient on a regular basis, the number of people visiting at one time should be kept to a minimum.

Conclusions

It is essential to keep all those involved in patient care as fully informed as possible. Yet one element of what we know about ADC has not yet been broached. Often patients with AIDS dementia complex are being cared for by their lovers,

who themselves are HIV-infected. It is becoming more common for counselors in metropolitan areas (like San Francisco, Los Angeles, and New York) to see couples where both members are demential. What happens when the caregiver has nothing left to give? What is being done to make sure that both the patient and the caregiver are receiving the kind of services they need? There are no easy answers, only hard questions.

What has been presented to this point has been an overview of the AIDS dementia complex. Representative cases were discussed. Treatment in forms of phase-specific care was described. Last to be emphasized was the importance of recognizing that those who help need help also. Much can be done to improve the quality of life of demential AIDS patients, to prolong their independence, and to foster a continuing sense of personal dignity. Likewise caregivers, family and professionals alike, need to maintain their sense of values and competence in work that is challenging and, at times, draining. This too can be accomplished by focusing on what is possible, working hard, and making a difference. Such is the challenge of AIDS dementia complex.

References

Boccellari, A., Dilley, J.W., & Shiore, M.D. (1988). Neuropsychiatric aspects of AIDS Dementia Complex: A report on a clinical series. *NeuroToxicology 9*, 381–390.

Centers for Disease Control. (1987, August). Revision of the CDC surveillance case definition for acquired immunodeficiency syndrome. *Morbidity and Mortality Weekly, 36* (supplement), pp. 3S–15S.

Cummings, J.L. (1986). Subcortical dementia. Neuropsychology, neuropsychiatry and pathophysiology. *British Journal of Psychiatry 149*, 682–697.

Dilley, J., & Boccellari, A. (1988). AIDS dementia complex: Diagnosis and management. *Focus: A Guide to AIDS Research, 3*, 1–3.

Navia, B.A., Cho, E.S., Petito, C.K., & Price, R.W. (1986). The AIDS dementia complex: II. Neuropathology. *Annals of Neurology 19*, 525–534.

Navia, B.A., Jordan, B.D., & Price, R.W. (1986). The AIDS dementia complex: I. Clinical features. *Annals of Neurology 19*, 517–524.

Navia, B.A., & Price, R.W. (1987). The acquired immunodeficiency syndrome dementia complex as the presenting or sole manifestation of human immunodeficiency virus infection. *Archives of Neurology 44*, 65–69.

Chapter 9

TREATING AIDS: A FAMILY THERAPY PERSPECTIVE

John H. Curtis

Little has been written about the family's struggle with acquired immune deficiency syndrome or about the reliance that a person with AIDS, ARC, or HIV seropositive status has on the family. Carter (1986) stated that "the effects of AIDS on the family and friends of the ill, the dying, and the dead and the hysteria surrounding this illness promulgated by many members of the press, and sadly, the scientific community, brings the figure of persons affected by AIDS into the millions." Simon (1988) elaborated on the severity of the effect of AIDS on the family by writing:

> Estimates are that by 1991, there will be 324,000 AIDS cases in the United States. Twenty-one thousand people with AIDS have already died. Taking into account the families, friends, and partners of those with AIDS, the disease will have an immediate impact on the lives of millions of people. Many believe that AIDS is the most serious health problem the United States has ever confronted.

With such an enormous impact on the American family, it is important for family counselors and therapists to explore ways to facilitate a family's functional adaptation to the various dynamics of the diseases associated with HIV. Many of these families will need help in dealing with the realities of the disease. Morin and Batchelor (1984) proposed:

> The mental health aspects of the AIDS crisis affect not only those with AIDS but also the people in their

lives. Lovers, friends, and family are all likely to experience significant distress and may need mental health services. Because AIDS is a mysterious and stigmatized illness, the psychological issues raised for significant others may be more complicated than those for other life-threatening illnesses.

The AIDS crisis presents family counselors and therapists with the opportunity to help families cope effectively. Walker (1988) stated that "surviving with AIDS depends in great part on determination, hopefulness, and improving the quality of one's life." Family-oriented counselors and therapists can help families focus on each of these to the benefit of the person with AIDS (PWA).

This chapter examines the use of a dynamic family approach to working with people with HIV infections and their significant others. After a brief description of family-oriented counseling, the chapter turns to an examination of current research conducted by the author, the results of which emphasize the importance of family involvement in the care of people with AIDS. The chapter continues with a discussion of important family issues, and concludes with implications for counselors.

Family-Oriented Counseling

During the past 30 years, family therapy and counseling emerged as a separate helping profession. Prior to this, the typical mode of therapeutic treatment was based on the interaction of one client with one therapist.

The theoretical development of family therapy has emerged from the concept that the family is a closed system. It is assumed that therapy can best be accomplished when all members of a family living unit are involved. This theory assumes that any change in any member of a family will automatically produce changes in the family system. Therefore, family therapists may see any member of a family separately, but typically prefer to interact with the whole family when dealing with families with AIDS or any other family.

Family systems theorists use a broad definition of the family. "Family" may be defined as the family of orientation, or procreation, or as the voluntary family in which a person receives nurture, love, and care. This latter definition is broader

than a blood lineage concept most often used by White middle-class families, and includes the functional concept often associated with rural Black families in which nonrelated persons fulfill kin roles. Prostitutes, homosexual men and women, drug users, and teenagers in gangs often form "voluntary" families where kin terms may be used (sister, brother, mother, etc.) but where there is no blood relationship. For the purposes of this chapter "family" is the group that fulfills the functions of family irrespective of blood lineage.

Although there is consensus concerning the broad definition of "family" by most family systems therapists, there is great diversity in counseling styles. These various styles have been organized into distinct schools of therapy with a variety of advocates for each approach. These schools include the psychoanalytic, behavioral, extended family systems, communications, strategic, and structural family therapies (Nichols, 1984). With the development of family systems theory and the recognition of family therapy as a separate helping profession, treating AIDS patients is an appropriate application of this therapeutic modality.

Research Implications for Family Counselors

Research into the various adaptations to AIDS, ARC, and HIV infection by families in the nonmetropolitan southern Georgia region has been a focus for the present author since 1984. Early studies included a statistical projection of HIV infections (cases of ARC, and AIDS and HIV disease) for each county in the state of Georgia (Curtis & Richardson, 1986). This project was followed by another that estimated probable AIDS-related deaths in Georgia county by county based on the formulas in their earlier work (Richardson & Curtis, 1986).

Preliminary Findings—Research in Progress

Another research project was designed by Curtis and Richardson comparing anticipated responses to an AIDS diagnosis among a homosexual sample and a heterosexual sample. The pilot study began 2 years ago with an in-class survey of 65 southern Georgia freshmen from an introductory sociology class.

They reported, in an open-ended survey, that if they contracted AIDS they would (ranked in order of frequency):

1. commit suicide;
2. flee the country; or
3. return home to their families for care until death.

The responses suggested that students would want to escape the hardship of AIDS (flight or suicide) if they could. The responses also suggest that more realistically, the students recognized the function of the family in caring for its ill members. This pilot study led to further research concerning what persons think they would do if they were diagnosed with AIDS.

During 1987, approximately 170 subjects were studied by interview and questionnaire to establish their anticipated actions to contracting any form of AIDS. Approximately one third of these subjects were homosexual men studied in a small town gay bar in southern Georgia. The second third of this sample was made up of members of a nationwide gay, lesbian, and bisexual professional group who gave the researchers permission to contact its members by mail. A third group of students from the nonmetropolitan southern Georgia college, who indicated they were heterosexuals, were included as a control group. A preliminary analysis of data in 1988 led the researchers to conclude that after exhausting their financial resources, most subjects from this study, if they contracted AIDS, would probably choose to return to their parents for care until they died.

Although the researchers do not propose that these findings can be generalized beyond the samples studied, the results of both studies suggested that people with AIDS might:

1. terminate their lives so as to relieve suffering and expense for the PWA and his or her family;
2. flee, so as to protect the family from the assumptions they might make if they knew the nature or cause of this disease;
3. exhaust all personal resources so as to remain independent as long as possible; and
4. return home to the family to die.

Regional Differences

Before examining issues for family counselors and therapists, the presence of some major regional variations in the

United States related to AIDS, ARC, and HIV spectrum infection should be explored. In San Francisco on Castro Street on a Friday night one can hear persons openly discussing their HIV-related symptoms and the new experimental drugs they may be trying. In southern Georgia, such a conversation would probably not take place. In general, New York and San Francisco may be a few years ahead of the nation in the number of cases diagnosed and services developed to assist PWAs. Other metropolitan areas probably lag behind New York or San Francisco by 2 years in feeling the full impact of HIV spectrum diseases. Nonmetropolitan areas experience an even greater lag. Consequently, there are vast regions where health care resources are still unprepared to deal with the magnitude of infections projected for this disease. In such regions, the primary education about AIDS is provided by the media, and the typical AIDS health care worker is a minimally trained public health department staff member.

For example, the southern Georgia region has few resources to help HIV-infected persons. Many medical doctors are not sophisticated in their understanding of this disease; until recently a person would often be told he or she had AIDS after a single ELISA test; this is an inappropriate and incorrect use of the ELISA test. A few area doctors admit to being reluctant to treat AIDS patients for fear of becoming stigmatized as the county's AIDS doctor and thereby experiencing a negative effect on their medical practices. In a small southern Georgia community, a transient PWA became ill and went for help to the local emergency room. When the PWA revealed to the doctor that he had been diagnosed with AIDS, the doctor gave him $100.00 from his wallet and urged him to catch the next express bus to Miami, "where they know how to treat this disease."

Wellness Associates, Incorporated, a nonprofit volunteer organization was formed in southern Georgia to provide confidential services to persons with HIV disease, ARC, and AIDS and their family members. All services from Wellness Associates are free. The services most often requested include advice on the AIDS crisis line, referral to medical and social agencies, and a support group for the HIV, ARC, or PWAs. Providing direct services to these persons has yielded numerous case studies that may or may not represent the ways that PWAs, persons with ARC, or HIV-infected persons are treated in other areas. Daily contact with the various clients

referred to Wellness Associates and their families suggested the following issues that can be addressed by family counselors and therapists.

Issues for Family Therapists

Family counselors and therapists, people with AIDS, and families must face many issues associated with this disease. The family counselor or therapist views the person with AIDS and his or her "family" as a system. Sometimes family systems will be dysfunctional and family counselors and therapists will want to gear their work toward increasing family members' ability to function in a healthier manner. In other cases, these dysfunctional family systems cannot be made functional. When this happens, the family counselor or therapist can still help family members and PWAs by redefining their goals so as to encourage the family members to cooperate *as much as possible* in the care of the ill (Molar, 1988). In addition to these therapeutic goals, the following themes will often need to be addressed in family therapy.

People With AIDS and Their Families Often Experience a "Double Leprosy" Effect

People with AIDS, persons with ARC, and people with HIV seropositive status typically come from highly stigmatized groups. In addition to the societal stigma, the seropositive individual may personally feel that he or she is a leper for having any form of HIV infection. Unfortunately, much of society, particularly in nonmetropolitan areas, treat people with AIDS and ARC like outcasts. This results in a "double leprosy" effect with the individual feeling like a leper and the society encouraging that impression. The following case example illustrates the double leprosy effect.

> Greg, a 29-year-old gay White man, had tested HIV antibody positive twice. Based only on these tests, a doctor inappropriately diagnosed his as a case of AIDS and transferred him from a general hospital to

a small psychiatric hospital where he was treated for depression.

Greg's family history revealed that his father and mother had divorced. Greg and his older brother had been raised by a grandfather, who served as the preacher for a very small, fundamentalist church in a small community. His mother had moved to Texas and remarried. His father remarried a woman with two small children aged 6 and 8 years.

Initial contact with the family was tenuous at best and demonstrated its dysfunctional character. Greg's brother did not want to deal with him because he was a "fag." His father was ashamed of him. His grandfather had publicly stated that he was "going to hell for all eternity." No one showed any interest in Greg. His stepmother announced that Greg could not enter her house because she believed he might pass his disease to her children. The brother's wife was pregnant so they did not want Greg to visit their home. Greg's mother called from Texas to tell him never to visit her and asked that he not let any member of her side of the family know that he had AIDS. Greg's grandparents said he could come live with them when he was released from the hospital, but that he would be restricted to his room. No one was to know that he had AIDS because Grandfather feared he would be fired from his pulpit. In summary, mother, stepmother, and sister-in-law feared the contamination of their children. Father, brother, and grandparents felt they could not cope with the fear of AIDS and its social repercussions in their communities.

Greg's position in the milieu of his community was one of severe stigmatization. When his situation was brought to the attention of a few community leaders, one lawyer suggested that Greg should be "bashed." When the lawyer was asked in a televised interview what that meant, he clarified his response and stated that Greg should be executed. All of this left Greg feeling as though his life were already over.

In addressing the double leprosy effect, family counselors and therapists will need to help infected persons like Greg feel positively about themselves and at the same time help the mem-

bers of the family to be supportive to their ailing family member. Unlike in many other therapy modalities, the family therapist may symbolically join the family (if it will let him or her do so) and design interventions that will encourage and support family change. Counselors need to pay special attention to the issue of "dual relationships," which are much easier to avoid in metropolitan areas than in nonmetropolitan areas where a face-to-face relationship often exists outside the office.

Families are More Resilient Than They Think

Generally, a counselor must start where the family is and help each member deal with his or her feelings. Learning about a family member's AIDS diagnosis confronts family members with issues related to death and dying as well as issues related to the transmission of the disease. Often the social and sexual behaviors that transmit the disease are judged as immoral.

Family systems counselors and therapists usually propose that families are more resilient than the various members think they are. However, it may take time for family members to accept the fact that one of their members has contracted AIDS. Ultimately, if the family counselor or therapist can keep family members talking to each other about their feelings and interacting with the person with AIDS, many families can learn to be supportive. The following vignette illustrates this.

> In December 1988 Don received an HIV-seropositive diagnosis. Because his partner had AIDS, their doctor suggested that Don would also probably develop AIDS; Don therefore chose to tell his parents that he was gay and that he had AIDS. In less than 10 minutes, Don's father and mother packed everything Don owned and removed him from the house. These events left Don devastated and he turned to the local AIDS counseling center where he received great support and a "surrogate" family. With a family counselor, Don worked toward reuniting with his family. Because of a strong southern family tradition of caring for dying members that transcends social prejudice, Don's father made steps toward reestablishing communication with his son.

Family Counselors and Therapists Need To Develop Skills for Working With Gay Couples and Their Families

With the advent of AIDS, homosexual couples are increasingly requesting help with their relationship problems, which are often brought into focus by a diagnosis of HIV disease. Consequently the family therapist must work to overcome any feelings of homophobia or "homo-negativism." Patten (1988) stated, that " . . . therapists, given some education and some positive interaction with gays, can learn to move past their hesitancy and awkwardness in working with people whose sexual orientation they do not share."

Patten (1988) found that gay couples were often angry and depressed after an HIV diagnosis. Fights about how (from whom) they contracted the infection are common. Privately, both might be afraid of losing their partner, of being abandoned. The family therapist will want to help gay couples realize that there is no need to panic. Patten suggested telling fighting ill couples that, "No one is dying right now. Your fighting is just a way of staying close while expressing your fear of being separated." Such reframing is often an effective strategy for the family counselor or therapist.

Family Counselors and Therapists Must Educate Families About AIDS

One of the unique functions of the family therapist is to answer families' questions and to help them pose questions as yet unformulated. Families will need to know that not all PWAs die immediately after a diagnosis. The perceptions of family members living in nonmetropolitan regions are confused, even though there have been public (media) educational programs about AIDS. Many family members do not know enough to distinguish between AIDS, ARC, and HIV disease. They consider "AIDS" as a single disease resulting in instant death.

Families will want to know if there is a danger that they can contract this disease, especially if children can be infected. Family therapists can assure all the members of the family that they cannot contract AIDS through casual contact. Even friends of people with AIDS who themselves are members of high-risk groups share this fear of contagion through casual contact. For example, when gay friends began to visit Greg after his release

from the hospital, many were afraid that they could contract AIDS from the visit. By watching his counselor treat Greg in a comfortable and relaxed manner, they became desensitized to their fear of AIDS. His gay friends soon functioned as his family during a time when his "blood" family was so uninformed and afraid of contagion that they could not help him.

Families Need to Adjust to the Person With AIDS's Long-Term Illness and the Probability of His or Her Death

The family therapist may become an agent in the death education for family members. Many persons are afraid of death and hence deny its reality. The person with AIDS who has already been to the hospital two or three times and whose immune system has broken down will need to confront his or her death. Although family members usually anticipate the death of an aged member, it is often difficult to plan for or deal with the idea of the death of the family's younger members.

In *Forum* (1987), Paul Volberding, the director of the AIDS program at San Francisco General Hospital, stated that the AIDS health care crisis involves two facets: acute care and chronic care, with chronic care for AIDS patients posing the most pressing problem and one that will worsen as the number of AIDS cases increases. Brody (1987) pointed out that the place where chronic care for the PWA is typically given is in the home. She explained that caring at home for a person with AIDS, a person with ARC, or an HIV-infected person may prove to be very "difficult at best, but is often a labor of love."

Families That are Unable to Provide for a Person With AIDS Require Special Interventions

Many families do not have the funds or the physical strength to cope with a family member's AIDS diagnosis. In these cases, counselors and therapists are often called upon to act as advocates and to almost magically provide resources. The following case provides one such example.

> Stephen was a young man with AIDS. He was referred to a counselor by his hospital who called wanting to discuss possible placement for him through a

District Task Force. The hospital administrator had allowed him to stay 2 months after all his medical benefits had lapsed and finally had to insist that Stephen be moved. Because of AIDS dementia complex, Stephen was seldom aware of whether it was day or night and was unable to feed himself. He was totally dependent and bedridden. Stephen's mother was quite elderly and when asked to take him, confessed tearfully that she could not lift him, change him, or give him the care he needed.

Rather than see Stephen left to die on the street, the counselor and task force worked out an intricate plan for Stephen that would guarantee his care. When the administrator of the hospital would no longer provide care for Stephen, an ambulance would take him to his mother's home. The drivers would unload him on a gurney and ring the bell. The mother would refuse him because she could not care for him. The ambulance drivers would refuse to take him back to the hospital and leave him on his mother's porch. The sheriff would watch this transaction and with a staff person from Adult Protective Services [Department of Family and Children's Services (DFCS)] would take custody of this abandoned adult, and call another ambulance to take him to the DFCS office. A judge would be asked to declare Stephen incompetent and abandoned. As an incompetent adult, and ward of the state, there was one hospital in the state where the law required that he be treated.

Cases like Stephen's occur in all parts of the country. As this case illustrates, counselors will need to be familiar with local resources, and the intricate workings of their region's health care system. Stephen's case also illustrates the need for additional resources and facilities to treat PWAs. States that restrict PWAs from nursing and rest home facilities need to reevaluate their policies. As the disease continues to grow, additional health care facilities will be needed. For the HIV-infected person, group homes and limited-care living facilities are necessities. Additional financial resources are also needed to provide minimum levels of care for those who have contracted AIDS when the family actually cannot provide the help they need for medical care, housing, clothing, home care, food, and medicine.

Families With HIV-Infected Children Need Special Care

Seeing young infants and children with AIDS can be heartbreaking not only to the family but to the counselor or therapist as well. Parents and foster parents of children with AIDS need support groups that provide an understanding for what caring for a dying child means. Counselors can encourage mothers and foster mothers to take "time out" without feeling guilty. They can encourage fathers and foster fathers to participate more fully in the daily care of the child. Counselors can help parents prepare for feelings of loss and grief when the child dies. Many families with HIV-infected children rise to the occasion and find that not only do they love the child more, but they are stronger and more loving among themselves.

Marriages That Include a Person With AIDS Can Be Quite Strained

Many issues related to a husband or wife's serostatus can negatively affect a previously successful marriage. Knowledge of a partner's past (or current) drug use or extramarital sexual activities often results in feelings of anger and guilt. Often husbands and wives are reluctant to continue having sexual relations with each other based on their fear of contagion as in the following case.

> Chuck was a drug user who was infected with HIV via a dirty needle. As his illness progressed, he lost the energy needed to work as an outdoor laborer. His wife began leaving him about once each month. When this occurred, he would move home with his parents for a day or two, work out a reconciliation with his wife, and move back into his home, only to bombard her with anger and hostility. In the marriage all sex was terminated and communication centered solely on the fact of Chuck's impending death. This resulted in his wife's feeling that Chuck did not love and care for her anymore. Chuck felt that he was a failure as a husband and was very ashamed of his disease.

Counselors can work with couples with infected members to facilitate more functional interactions. When wives are willing

to support ailing husbands, counselors can help the couple see the change of traditional roles as a sign of love. Counselors can help couples find ways to avoid terminating all sexual sharing and instead practicing safer sex. Family counselors and therapists will need to be sensitive to the terrific sense of guilt that husbands and wives experience. Unless it is examined, this guilt will have an adverse effect on the couple's marriage.

All of the themes discussed above indicate that the person with AIDS, ARC, or other HIV infection needs the support of family and friends. The following 9 family support factors can be used by families with or without the guidance of a counselor to improve the quality of life for an infected person.

Family Support Factors

1. Family members should become familiar with social service agencies and the help that they provide for PWAs.
2. Family members and the PWA need to be open and honest in expressing their attitude toward this disease. Honesty seems to be the most important factor of continued open family communication.
3. If the family can afford therapy with a counselor, then the family and the PWA should be helped to deal with fear, guilt, and attitudes toward death.
4. A person with AIDS's partner lover spouse should always be included as a member of any family group whenever the family will tolerate this. The rights of spouses or lovers need to be guaranteed and their guilt and grief addressed.
5. Regardless of the past life style of the PWA, each PWA needs compassion and support. Families should view this disease as if it were any other life-threatening illness (i.e., cancer) and react with the same loving care that they would give to any dying member.
6. Regular contact with former friends and associates should be encouraged even when the PWA is very sick and dying. Often this is difficult for the family and friends of a PWA, but necessary for the maximal functioning of the dying person. Talking about the good times of life, planning for the funeral, making a will, and occasional bargaining with God for an immediate cure are

all a part of the struggle when persons find that they must die. These tasks are often less painful when shared with family members, lover(s), and friends.

7. Spiritual needs, which vary from person to person, need to be respected. Compassionate clergy, desensitized to AIDS, prove very helpful to the family, friends, and the PWA.
8. Family members should help the PWA deal with the realities of terminal illness. As long as the PWA feels well enough, he or she should continue with former activities and friends.
9. Family members and the PWA must learn to deal honestly with fear, anger, guilt, depression, and other related problems. In such dealings no one should take personally things said or the panic that each person occasionally feels. Families need to remember that an honest, open, encouraging attitude will help everyone involved, even when each is helpless. The person with AIDS cannot change his or her disease. The family cannot change the disease. However, both the family and the PWA can change the emotional context of their attitudes toward AIDS if they will educate themselves and deal honestly with it.

Implications for Family Therapists

It is important that family therapists as well as others in the various helping professions realize that one of the effective ways to help PWAs is through family-oriented therapy. No one lives their life in a vacuum. The PWA may wish to conceal the disease from family members in order to "protect" them from its grim reality. However, in so doing, he or she still sends the family messages that something is wrong. Although it is unlikely that a family member can correctly anticipate the exact nature of such atypical behavior, family members often have a general sense that something is not right. For the most part, family members can cope better with what they know, even if they do not particularly like it, than with what they suspect.

In the family milieu there are those whose duty it is to provide care for the dying. Families can rise to this occasion. They can be most effective if they are helped by a therapist to

desensitize their fear of AIDS and become supportive. Families can be the primary care providers for PWAs and an effective home/family-based program of health care can prove vital to the needs of a person with AIDS.

If a family therapist helps the person with AIDS and his or her family members deal honestly with their emotions, the various stages of dying can be facilitated so there is a minimum of pain for those involved. This implies that no one can deny the realities of AIDS, ARC, or HIV seropositive status, no matter how attractive false hope or denial may seem to be. Family members and the PWA need to practice healthy emotional disclosure if they are to be functional. At the same time the anger and guilt that so often accompany this disease can be dealt with. Families need to be given permission to experience these feelings. In that way, they can grieve together and provide each other with social support as they deal with the death of a family member and, vicariously, with their own death.

As the disease progresses, there are often occasions when the patient will feel rather well, which creates false hope for the family. When the disease reoccurs, the patient and family may feel that they have been on a roller coaster. If families are to cope effectively with this prolonged illness, it is extremely important that they give each other brief intervals away from the situation where they can renew their coping abilities.

Conclusion

Family counselors and therapists see the person with AIDS, ARC, or HIV-positive serostatus and his or her family, be that parents, husband or wife, lovers or friends, as a system. In the face of AIDS, these systems need encouragement. As discussed in this chapter, the role of the family counselor or therapist is to join the family, act as a coach, encourage the family members, and demonstrate that he or she is unafraid of this disease. As a consequence, family counselors need to be desensitized to AIDS, drug use, homosexuality, prostitution, promiscuity, and a number of other related socially stigmatized behaviors. Once desensitized, the family therapist can provide the role model that helps family members and the PWA remain stable in the midst of this family crisis. The family therapist can help the

family change so that they provide compassionate care and at the same time experience a closeness that reassures each member that he or she did all they could for their dying member. Such therapy is time-consuming, but it facilitates dying with dignity for the person with AIDS and caring with compassion for the family. Counseling that helps the infected person and his or her family members deal with their sense of loss, grief, and the realities of AIDS may be the most effective treatment available at this time.

With help, the family can be the resource that best helps the person with AIDS achieve a high quality of life after his or her diagnosis. Whether in a small nonmetropolitan region, where there are relatively few resources to help people with AIDS, or in large metropolitan centers, families are going to need ongoing support, financial help, and encouragement. Family therapists, who prepare themselves to effectively educate and provide direct services to persons with AIDS, persons with ARC, or HIV infection, often with little financial reward, are doing pioneering work at the edge of this pandemic. In this work, every gain means hope for the people of the world for whom AIDS has become the feared disease of the 1980s and quite possibly the 1990s.

References

Brody, J.E. (1987, October 28). Personal hell. *New York Times*, offprint.

Carter, D.B. (1986). Aids and the sex therapist: "Just the facts please Ma'am." *Journal of Sex Research, 22*, 405–408.

Curtis, J.E., & Richardson, M.M. (1986). *The epidemiology of AIDS in Georgia: An analysis of statistical projections for Georgia, metropolitan Atlanta, and each Georgia county, 1985–2000.* Unpublished research report.

Forum. (1987, September-October). The impact of AIDS on death education, counseling, and care. Santa Cruz, CA: *Newsletter of the Association for Death Education and Counseling.*

Mohr, R. (1988). Deciding what's do-able. *The Family Therapy Networker, 12*, 34–36.

Morin, S.F., & Batchelor, W.F. (1984). Responding to the psychological crisis of AIDS. *Public Health Reports, 99*, 4–9.

Nichols, M.P. (1984). *Family therapy: Concepts and methods.* New York: Gardner Press.

Patten, J. (1988, January-February). AIDS and the gay couple. *The Family Therapy Networker, 12*, 37–39.

Richardson, M.M., & Curtis, J.H. (1986). *Predicted AIDS related deaths in Georgia: 1985–2000.* Unpublished research report.

Simon, R. (1988, January/February). AIDS and family therapy. *The Family Therapy Networker, 12,* 33.

Walker, G. (1988, January/February). An AIDS journal. *The Family Therapy Networker 12,* 29–32.

Chapter 10

MODERN HOSPICE CARE

Sr. Patrice Murphy and Carole Donovan

When a person becomes seriously ill, there comes a time when no further treatment can be offered to reverse the ravages of the disease. What is needed are measures to promote comfort, to alleviate such symptoms as nausea and diarrhea, and to prepare for a peaceful death. In short, what is needed is hospice care—a health care approach that embraces and supports the patient without searching for unobtainable cures. Hospice care traditionally was offered to persons who suffered from cancer or other illnesses in which a 6-month prognosis could be determined. With the emergence of the AIDS epidemic it became clear that those afflicted with AIDS could benefit greatly from receiving hospice care.

In 1967, St. Christopher's Hospice in Sydenham, England, opened its doors to terminally ill persons who had cancer and began a revolution in health care. Dame Cecily Saunders, its founder, believed that care at St. Christopher's "... should stem from respect for the patient and very close attention to his distress ... to plan and carry out research in the relief of distress such as has not been done anywhere else" (Saunders, 1965, p. 1615). St. Christopher's demonstrated that patients could be helped to live to the fullest—even when death was only hours away.

It was through the work at St. Christopher's that pain relief without severe drowsiness became a reality. Studies carried out there demonstrated that an analgesic titrated to the degree of a person's pain could eliminate that pain most of the time yet enable the person to participate in the life around him or her.

Although St. Christopher's opened its doors 21 years ago, hospice care is not a new concept. The term hospice originally

described a stopping place for pilgrims in medieval times. In this country it has come to represent a type of care rather than a place of care. That is, it is care that is concerned with making patients comfortable so that they can continue to live as fully as possible in the remaining time of their life. Pain is controlled, nausea subdued, appetite encouraged, weakness supported. Hospice care is generally provided to terminally ill persons whose prognosis is estimated at 6 months or less. The care can be provided in a free-standing facility, in a hospital, or in the patient's home. The first hospice program in this country was The Connecticut Hospice, Inc. in Brandford, which began providing care in 1974. Currently there are over 1,600 hospice programs throughout the United States. Of these, 625 are Medicare certified. States vary in their requirements concerning licensure.

With the increasing numbers of persons infected with the human immunodeficiency virus (HIV) and ill with AIDS, it became clear that hospice care was an appropriate part of their health care. In a report to Health and Welfare Canada, the Expert Working Group on Integrated Palliative Care for Persons with AIDS stated that "... as the present outcome is always fatal and much shorter than cancer care in general, preparation and integration for death should begin at diagnosis" (1987, p.16). Thus, while active aggressive care can be directed toward controlling symptoms and disease, those issues concerning the eventual death of the patient are, therefore, incorporated into the early care of the person with AIDS. Such issues include informing others of the patient's terminal illness, expressing the patient's grief concerning his or her losses and impending death, completing a will, and designating someone to have power of attorney and durable power of attorney.

The Supportive Care Program at St. Vincent's Hospital and Medical Center in New York City began working with AIDS patients in late 1983. The staff decided that patients who had AIDS could be accepted at any point in their illness when the Supportive Care team could be helpful. The usual hospice guideline of a 6-month prognosis was not imposed because it was not clear how this timeframe could be determined in these patients. The illness and its course were entirely unpredictable. Often by taking patients into the program at what turns out to be an early state of their illness has been valuable. The staff have come to know the patient and his or her coping styles when illness has not been overwhelming.

Modern comprehensive hospice care is composed of basic tenets. These tenets include: patient and family are the unit of care; care is managed by an interdisciplinary team; trained volunteers supplement and complement the efforts of professional staff; focus of care is on symptom management; hospice care is available on a 24-hour, 7-day-week basis; and bereavement care is available to loved ones after the patient's death.

Patient and Family—The Unit of Care

For persons with AIDS (PWAs) the term family is frequently broadly defined. Some have strong ties with their family of origin as well as significant relationships with carefully chosen others. Others may have moved away from their parents' house at an early age because they were aware of being "different" and of needing to seek the closeness and companionship of others like themselves; this is frequently true of the gay PWA. Although these individuals may maintain cordial realtions with parents and siblings, they often share little about their personal lives and life styles or may share this information with only one family member.

Still others have been rejected by parents or siblings because of their homosexuality or use of drugs. Attempts at reconciliation by sons or daughters may have been fruitless. Disappointment, sadness, and anger mount on each side.

A small percentage of PWAs are individuals who initially denied their gay sexual orientation and pursued a heterosexual life style—often marrying and fathering children—only to find at some point that they could no longer live a lie and subsequently were impelled to seek a divorce. Another small percentage of PWAs, whose numbers are growing rapidly, are those who have become infected because of an IV drug history, and who, in turn, are infecting wives or girl friends and their infants. Confusion, shock, fear, and rage are emotions frequently experienced by family members of such persons if or when the infected individuals reveal their situation. A small percentage of PWAs are bisexual and their extramarital sexual activities have led to their infection. Finally, there are those PWAs who have contracted the disease because they received transfusions infected with the HIV.

When hospice workers speak of family and people with AIDS, they are talking about those with family created by blood

relation, those created by the individual's choice, and those created solely of the professionals or paraprofessionals caring for the patient. Hospice workers supporting PWAs and their families are not only dealing with the patient's terminal illness, but with a myriad of charged issues and emotions of family members including homophobia, fear of contagion, shock, guilt, shame, anger, sorrow, secrecy, and ambivalence. Availability of hospice staff to family members for discussing issues, sharing emotions, and confronting fears and ambivalence is of major importance in the care of both patient and family. Often hospice staffs, by their warm and caring actions and attitudes toward the patient, serve as role models to those loved ones who are uncertain or fearful in their approach to the patient.

It is not uncommon for many parents to learn that their son is gay at the same time they learn that he has AIDS. Jack, for example, did not want to tell his burly truck-driving dad that he had AIDS and that his illness was related to his gay life style. His mother urged him to include his dad in the sharing of this information as did his hospice nurse. When Jack did, his father responded, "You're my son. I love you no matter what." Tom, on the other hand, called his dad to inform him about his diagnosis and to ask for some financial help. On hearing about Tom's diagnosis, his dad replied, "The wages of sin are death." That was the last Tom heard from his father.

Peter called St. Vincent's to ask for help in working with his sister. Peter, who was 38 years old, had been diagnosed a year before with Kaposi's sarcoma (KS). Like Rock Hudson, he had been treated in Paris, but without success. His KS lesions most severely affected his face. His eyes were nearly closed because of the extensive swelling of his lids. His nose was large, almost bulblike and black. In fact, it looked as though someone had replaced the tip with a large black olive.

Peter's lover had left him the fall Peter was diagnosed as having AIDS. That Christmas, Peter was to spend the holiday with his sister, Judy. He called to tell her his diagnosis. Judy called him back and told him that he could not visit for the holiday. In fact, he could not visit in her home at all. Her husband had recently recovered from a serious illness and did not feel secure about having Peter there.

Peter was anguished and angry. He wanted the hospice team's help because he feared that Judy would be guilt-ridden following his death. They had always had a close relationship.

Both parents had died and they were all that remained of their family. The nurse who visited Peter listened to his concerns and to his anger about Judy. She spoke with Judy and heard her anguish at not being able to be with Peter. Judy's husband would allow Judy to visit Peter, but only if they met in a public place, not Peter's apartment, and Judy was not to touch him. Judy felt a deep conflict between her love for her husband and love for her brother. To help work out some of the issues of forgiveness and conflict, the nurse arranged for a young priest who volunteered with the program to meet with Peter.

In time Peter was able to say that he forgave Judy. Judy was able to put aside her conflicts and meet Peter and hug him. Although Peter had a number of physical problems that required attention, it was really the issue of his relationship to Judy that troubled him most. When that work was complete, Peter arranged to have one last weekend in the Catskills with his friends. He wanted to see a starry sky, to play Trivial Pursuit, and savor a world he was ready to leave. When the weekend was over, his friends had to piggyback an exhausted, weakened Peter up the stairs to his apartment. Within 2 days, Peter died quietly in his sleep.

Conflicts between the PWA and his or her family may ultimately never be resolved. Those PWAs and their families affiliated with a hospice program whose staff is prepared, skilled, and sensitive to the possible wide range of family reactions, reap the benefits of the efforts of these professionals and volunteers. Not infrequently, patients and families face death reconciled and peaceful.

Hospice Care is Managed by an Interdisciplinary Team

Physicians, nurses, social workers, pastoral care persons, and trained volunteers make up the core hospice team. Many of these individuals have devoted themselves to hospice work out of a sense of frustration and dissatisfaction with the limitations of institutional care of the terminally ill and a cogent desire to use their skills and talents to improve this situation for others. By working together with a sense of interdepend-

ence, they found they were better able to share and coordinate their philosophies and goals of care and thus more fully meet the manifold needs of the terminally ill patient and family. When the individual team members respect and appreciate one another's expertise and special gifts of mind and spirit, and when conflicts are recognized and resolved quickly, the team is not only a source of strength and support for patients and families but also for one another. This is no small advantage.

The roles of hospice physician, nurse, social worker, and chaplain are familiar to most people, but the role of the volunteer in the service and support of the terminally ill is less well recognized. Volunteers have been the backbone of hospice care since its inception in the United States and are unique among those rendering services to patients and families. What do hospice volunteers do? The possibilities are endless. Volunteers can visit a patient, read to him or her, take the patient for a walk, for coffee, to a movie or a play, bring the wheelchair-bound patient for a ride outdoors, cook a meal, listen empathetically, explore issues with the patient or family, comfort family members, and provide respite for caregivers. The occasions for volunteers to be a caring presence to the patients and families are as many and varied as the individuals involved.

Volunteers do what they do because of a desire to serve in a way that is not concerned with the usual problems of earning a living. They have special and unusual motivation; a price tag cannot be attached to their special gifts of self and service. Volunteers humanize services by extending and enriching the care rendered by staff whose duties often do not allow them time to provide the "extras" that often they wish they could offer. There will never be enough people to meet the deep human needs of the sick and dying and their loved ones.

The increase of individuals interested in assisting PWAs has occurred steadily since the beginning of the AIDS crisis. Many large communities have developed a variety of volunteer groups, and hospice is a setting chosen by many volunteers for their services to PWAs. However, a volunteer program costs money. Recruiting, screening, training, supervising, and supporting volunteers is expensive when done well, but the finished product justifies the price. Volunteers to PWAs and their loved ones have proved to be a priceless ingredient of the total blend that constitutes hospice care.

In a hospice team there are times when roles may blur. A social worker may notice a change in a patient's way of relating

or a physical manifestation previously unnoted that may herald the beginning of a new symptom. Hospice nurses may find themselves counseling patients and loved ones and establishing in-depth realtionships. Hospice chaplains often find themselves advocating for patients' rights. Blurring of roles is all to the good, and where team members are united in their philosophies and goals, such role blurring can result in maximizing support and comfort for patients and loved ones.

Pastoral care can often be an area of role blurring because all team members are involved in responding to the spiritual side of their patients. In approaching patients and loved ones with a deep respect for the intrinsic value of each human being and a nonjudgmental acceptance of the person as unique, caregivers are responding to the most basic spiritual need of all human beings. Often respect and acceptance of this quality serve as a foundation for further work by patient and pastoral counselors in facing the issues and needs that emerge when patients are confronting death.

Persons with AIDS do not always raise existential questions with the hospice chaplain or pastoral counselor. Nurses, social workers, and even volunteers may be confronted with questions or statements such as: "Why is this happening to me? I never hurt anyone." "Is God angry with me?" "Some people say I brought this all on myself." "What is dying like?" "Will I be brave enough?" "I'm not afraid of death, but I'm afraid of dying." Sometimes there aren't responses to these statements or answers to the questions. At other times, exploring with the patient who his or her God is and what his or her life journey has been like thus far may facilitate a discussion whereby the patient will arrive at his or her own answers. It is always helpful for the caregiver to reassure the patient that hospice staff members will do everything possible to relieve pain or other bothersome symptoms whenever they occur.

Are we, as professional caregivers, as members of a team, ready for such questions? We are if, in working with terminally ill persons and their loved ones, we have learned to face our own mortality, if we have examined the fears and hope in our own hearts and spirits, if we are in touch with the depths of our own beliefs, and if we believe that each person's spirituality, including that of the caregiver, is unique yet always involved with relationships—relationship to self, relationship to others, and ultimately relationship to God or whoever God is for the individual.

Hospice Availability: 24 Hours—7 Days per Week

This tenet of hospice care is a difficult and often costly one. The ideal being sought by this requirement is continuity of professional care and caring, that is, the availability of hospice-prepared individuals on a continuing basis, uninterrupted by the closing of offices and weekend or holiday breaks. Each program, true to its commitment to comprehensive hospice care, must seek out its own method of best responding to this tenet of care. Examples of meeting this prescription have been the utilization of carefully trained and highly motivated professional volunteers who take turns being "on call" during each month, or the hiring of per diem staff for the hospice whose sole responsibility is being "on call" after hours and on weekends and holidays, particularly for those hospice patients who are in their own homes.

Despite the difficulties involved in meeting this particular criterion, instances where patients and loved ones have used this service prove its importance to both the physical and emotional well-being of the patient and loved ones. Patients with AIDS who often have high anxiety levels may find themselves panicked by a change or increase in a symptom such as a rise in temperature. Vulnerable and emotionally drained loved ones may find they need the reassurance and support of a caring hospice professional. Often telephone contact will serve as the means of soothing or providing directions or explanation. Listening may be the most effective therapy a patient or loved one can receive. Some calls may require a visit from the "on-call" person in order to assess the situation, and some situations may require the professional "on-call" person to be the liaison between the patient and physician or pharmacy or volunteer, depending on the circumstances and the outcome of the assessment. It is significant how often this service has meant the difference between maintaining a patient at home rather than rushing him or her to an emergency room where impersonal and sometimes highly technical modalities of treatment not desired by the patient or loved ones may be utilized. Whatever the need—be it only a patient's need to check that there is truly someone "on call"—strength and caring is communicated to the caller.

Sometimes a call may come to the "on-call" person from a loved one saying that he or she thinks that the patient is dying or has died. Shock, sorrow, and confusion may be evident in

the caller's voice, and the response of the alert, caring "on-call" hospice person can make a tremendous difference in how a patient or loved ones face and respond to this event and how the memory of that powerful experience will affect them in the future.

Management of Symptoms

The hospice movement vigorously stands against the aseptic walling off of the terminally ill patient from him- or herself and from other human beings. Rather, it offers a carefully designed program of "loving care" where all caregivers are sensitively attuned to recognizing and responding to the needs and the rights of the terminally ill (Anderson & MacElveen-Hoehn, 1988). Needs may include affirmation and validation of decisions, privacy, independence, and the desire to continue living life as normally as possible. Rights often include being included in all plans for one's own care and treatment, receiving full information regarding options available in treatment, or stopping treatment as well as continuing it.

Expertise in managing pain is perhaps the best recognized contribution of the hospice concept and philosophy to terminal care. Because oral preparations and rectal suppositories of many effective pain medications are available in local pharmacies, it is frequently possible to work out pain control in the patient's home. Some pain medications are available in time-release capsules whereby relief is spread over long time periods. Hospice team members are knowledgeable about dosage and side effects and readily recognize untoward symptoms that may indicate an unwelcome side effect of a medication. It is often this specialized knowledge and expertise that has gained hospice care its recognition and acceptance with patients, families, and physicians.

Persons with AIDS tend to have many symptoms during the course of their disease process, and their management can be complex. Discussion of symptoms begins with their unpredictability. Thereafter, consideration of symptomatology entails familiarity with each body system. For the purpose of this chapter, discussion of symptoms is limited to unpredictability, anxiety, depression, and suicide.

Unpredictability

To take on the care of PWAs is to take on uncertainty. Most hospice staffs have grown familiar with the terminal illnesses from which patients in their programs die. They have accumulated data on the course of diseases and the probable impact that appropriate treatments or their lack will have on the trajectory of the illness. Hospice staffs are able to anticipate difficulties and often prevent them because collective experience has sharpened their sensitivity and intuition. With AIDS the scenario is very different. There is no long history of experience in managing the disease, and therefore, there is a decreased comfort level for the professional caregivers. Some symptoms and the processes causing them are rare and occur without warning, such as spontaneous pneumothorax (collapsed lung) and cardiac tamponade (compression of the heart that can lead to standstill), and require acute and intensive management in hospital. Other symptoms are frequent and apparently simple to treat, but these treatments present varying levels of difficulty and success. Among these are a fungal infection (thrush) in the mouth or esophagus, chronic diarrhea, fever, anorexia, and dehydration. Tumors such as those of the walls of blood vessels (known as Kaposi's sarcoma) can cause problems in many different parts of the body—skin, oral mucosa, palate, gastrointestinal tract, lungs, liver, and spleen. Sometimes these occur concurrently. Whenever and wherever these occur, they challenge the knowledge, understanding, and ingenuity of the most skilled caregivers. Although Kaposi's sarcoma may be the more common malignancy seen in PWAs, non-Hodgkins lymphoma, an aggressive malignant tumor that can be found anywhere from rectum to abdominal cavity, from chest wall to nasal septum to brain, is all too frequently diagnosed in persons with AIDS. Both chemotherapy and radiation therapy have been used in treatment. Response has varied; no treatment has eliminated the tumors, which alone or in combination with opportunistic infections, lead to the death of these patients.

Among the infections that occur in these patients are those caused by protozoa. Pneumocystis carinii pneumonia (PCP) can be an insidious or rapidly progressing lung infection. Toxoplasmosis can cause an infection in the brain or lead to visual loss. Cryptosporidiosis is commonly known as traveler's diarrhea, but may be more persistent in the PWA. Cytomegalovirus is a

herpes virus that can affect the eyes, liver, lungs, and brain. These diseases can often be treated but never cured. Many treatments have their own set of complications that can also be debilitating and even life-threatening, such as low white blood cell count (neutropenia), a low platelet count (thrombocytopenia), severe skin reactions, high or low glucose levels, and renal damage.

Anxiety

The threat of exposure to the HIV virus and the fear it inspires have forced people to develop a variety of coping mechanisms ranging from denial to substantial adaptation. When coping mechanisms are inadequate, fear may increase to the point where it can become irrational and prompt maladaptive behaviors that are debilitating and destructive.

Most of the research to date on anxiety and depression in PWAs has been with the gay or bisexual population. Intravenous drug abusers, who have their own special problems, do not usually find their way to private or clinic therapy or into research studies. Many PWAs experience guilt and shame and expect punishment; they may feel anger and resentment toward other gay individuals suspected of infecting them. There may also be a simultaneous concern and regret for other PWAs for whose infection they may feel responsible. Shame and guilt contribute to serious loss of self-esteem that in turn may lead to social withdrawal, an increase in depression, and even suicide.

In an article entitled "Psychotherapy and the AIDS-Anxious Patient," C. Richard Filson and Charles R. Tartaglia (1988) concluded:

> "... Despite the shifts in the issues patients face after diagnosis, problems maintaining self-esteem, retaining a clear sense of identity, finding meaning in day to day activities, holding on to important relationships, preserving a sense of control often require a therapist's assistance ... active engagement of the patient, understanding the meaning of symptoms (such as fear of death or disability) and determining psychological characteristics and coping styles are techniques which can help therapists in their efforts to provide care. (p. 2)

Depression and Suicide

In a recently published study of suicide in persons with AIDS in New York City, Marzuk, Tierney, and Tardiff (1988) provided the first epidemiologic documentation for a distinct relationship between AIDS and the act that, above all others, signals desperation and hopelessness—suicide. The study indicates that in 1985 the rate of suicide among New York City residents with AIDS (61.4 deaths per 100,000 persons per year) was 66 times higher than that of the general population of New York City. Men 20–59 years of age with an AIDS diagnosis were 36 times as likely to commit suicide as were men in the general population of New York City. The authors note that it is likely that these figures underestimate the true AIDS-related suicide rate.

These facts confirm the suspicion of many professional caregivers of persons with AIDS and reinforce the need for physicians, nurses, social workers, and pastoral counselors to explore openly the issues of suicide where the risk of suicide is suspected. The patient with overwhelming feelings of panic, guilt, shame, depression, and hopelessness, and the one with the neurological complications of delirium or dementia are acknowledged to be at high risk for suicide.

Preventive measures to reduce the risk of suicide are similar to those used with patients suffering from other serious illnesses. Opportunities for open discussion of feeling surrounding diagnosis; fears of disability, deterioration, and ultimately death; guilt over fractured but important relationships or over the embarrassment caused loved ones; and frustrated desires to retain some control over their lives are crucial issues for "at-risk" patients to explore with trained hospice team members.

Neuropsychiatric consultations must be sought where there is evidence of complications such as marked depression, dementia, or delirium. Such complications should be assessed and treated in order, if at all possible, to maximize the quality of the patient's life. Marzuk et al. (1988) stated, "Caring for patients whose illnesses bring them to the painful extremes of human experience has always been one of the most challenging aspects of the physician's role." This statement can be equally true for hospice nurses, social workers, pastoral caregivers, and volunteers.

When one reflects on the array of possible symptoms that the person with AIDS may manifest, there seem to be three

primary courses that the disease may take and of which each hospice team member needs to be aware. Severe sudden opportunistic infections such as pneumocystis carinii pneumonia and death; gradual decline with periods of relative stability between acute episodes; and lastly, a course characterized by a combination of the other two such as an acute sudden first illness, gradual decline, and then an unexpected death during a period of what was thought to be stability.

Sudden unexpected deaths are not the norm in hospice care. Usually there are clear signals that a patient's condition is deteriorating; loved ones and staff have an opportunity to say final goodbyes. With AIDS, unexpected and sudden deaths occur with some regularity and are upsetting to everyone involved. Such rapid, unanticipated, irreversible decline adds to the level of fear, powerlessness, and uncertainty for all.

Timmy is an example of a patient in the last category. The hospice team at St. Vincent's met him in the hospital during his initial opportunistic infection of PCP. Timmy was in his 30s, had come to the mainland United States from Hawaii where his parents and sibling lived. He was an unusual man with a winning smile. Even in the throes of a 105-degree fever and severe shaking chills he never complained. Timmy had a special friend with whom he lived and he worried about him. Always, his concern was more for his friend than himself; when with his hospice caregivers, he would always try to divert their attention away from himself toward his friend. Although most of the hospice teams' experience with Timmy was in his home, he required hospital admission on two occasions for unexplained fevers. During the last admission, when he was not in bed with fever and chills, Timmy was ambulatory, visiting some patients confined to their rooms and chatting with others in the lounge. He was much loved by staff and fellow patients. During the night following a relatively comfortable day, the nurses on their rounds found Timmy pulseless and not breathing. Emergency resuscitation efforts failed to bring him back to life. A great sadness descended upon staff and patients on Timmy's unit and on the hospice staff who had cared for him at home.

Symptom management is no less a challenge to the social worker or pastoral care provider on the hospice staff than it is for the hospice physician or nurse. Patient and family comfort levels are only satisfactorily addressed when each team member's goal is excellence in assessment, observation, sensitivity, communication, and intervention.

Bereavement Care

Bereavement services complete the continuum of care provided by hospice caregivers to the patient's loved ones. Services are offered after careful assessment of the needs of the primary griever(s) and with great respect for the individuality and desires of those grieving. These services can be as simple as a periodic phone call to ask "How are you? We're thinking about you." They can be more structured, with regularly planned phone calls by a staff member or a volunteer, or they may take the form of participation in a bereavement support self-help group. However, it is most important to realize that bereavement services ideally begin prior to death with both the patient (if this is possible and appropriate) and with loved ones. Grief work that begins before the patient's death is called anticipatory grieving.

The Patient

We all, as caregivers, recognize that grief and mourning are a normal and appropriate response to loss, but not everyone acknowledges that the terminally ill person also grieves. For patients with AIDS, grief may begin with the diagnosis and further intensify as the disease progresses. The accumulation of losses for these patients with AIDS can be great depending on the length and degree of illness. Physical appearance, youth, and beauty are highly valued in our culture, especially in the gay subculture. PWAs grieve the loss of their appearance. Handsome young people with special gifts of charm and sensitivity gradually, or sometimes quickly, lose the appearance of which they were so proud. Significant weight loss, muscle wasting, thinning of hair, dramatic purplish lesions, fatigue, and listlessness lead to drastic changes in appearance, and often the once-handsome young person may be barely recognizable or not recognizable at all. Society is learning that having an appearance that resembles a walking skeleton or a concentration camp prisoner can be a telltale sign of AIDS; this may make public activities awkward and uncomfortable for PWAs. It may mean loss of livelihood. The fatigue associated with AIDS can be overwhelming and often precipitates lateness for work, absences, and inability to produce as effectively as previously.

Eventually, the patient must confront his or her inability to continue to hold down a job. Loss of job heralds loss of income, perhaps also the ending of insurance coverage. The PWA with gradually diminishing resources becomes dependent on the goodness and generosity of relatives, friends, or the entitlements available at city and state levels.

All too frequently PWAs face the loss of relatives and friends. Family members—shocked, ashamed, and righteous—may completely reject or withdraw coolly so that their emotional involvement in the plight of the PWA is negligible. Friends, often young, frightened, vulnerable, and confused, may withdraw gradually but noticeably. The patient's grief deepens. These losses have profound implications for the sick person because the caring presence and attentiveness of loved ones, even in the face of terrible debility and impending death, is a source of hope and comfort to the dying patient.

Just as counselors have roles in society, in professions, in family, so too, did those now diagnosed with AIDS. When an actor can no longer act, or an artist can no longer paint, or a physician can no longer heal, his or her concept of self diminishes. Hopelessness may follow.

Loss of life—one's own— can be incomprehensible to the young PWA. Usually young people in their 20s and 30s have had little life experience with significant personal loss. Perhaps a grandparent with whom he or she felt close ties has died, but even that contributes little to preparing a young person for his or her own death. At an age when most young people feel immortal, and society—a death and grief denying society—perpetuates that myth, PWAs have usually never even imagined dealing with their own death.

Looking at death at any age clearly is not easy. Some PWAs seem to operate on two levels when talking about their death. On one level, they believe and hope they will survive long enough to see a cure found. They seek out alternative therapies such as healing groups, acupuncture, and diet as a way to stave off death. They look to returning to work as a way to confirm that life is going to go on as before. On another level, they prepare their wills and assign power of attorney. Somewhere in the progression of their illness, they begin to accept that physical losses will not reverse and that death ultimately will be the outcome of their disease.

What moves a patient toward understanding that he or she will die from the disease is unclear. Surely being emotionally

supported by a caregiver who listens, who suggests measures to alleviate symptoms, who cares, provides the safe environment in which even the most terrifying events can be considered.

Confronting death is often as difficult for the parents, siblings, lovers, and close friends of the PWA as it is for him or her. Not only is it difficult to confront death, it is also difficult to express one's grief in a society that has little sympathy for those who have contracted AIDS. The survivors—the family, friends, and lovers—often become "hidden grievers."

Loved Ones

Experiences with these grieving individuals have demonstrated the terrible isolation and secrecy with which loved ones often surround themselves, closing themselves off to the supports ordinarily available for those who grieve. Often they respond in this way because they are frightened. Parents frequently tell no one the truth about their child's death. They fear that the truth could mean loss of their support systems because of the stigma of AIDS, fear of contagion, and moralistic reasons. They live a lie and grieve quietly and alone.

Lovers and close friends are "hidden grievers" because they also are afraid—afraid of the fallout for themselves—if people knew the depths of their grief and its reasons. They are afraid of losing their jobs or apartments or business associates, afraid of overburdening their friends and causing them to withdraw, and afraid for their own health or lack of health. They are in the midst of a process they can barely define let alone acknowledge.

Grief is a normal, natural, and lengthy process; it has a beginning, middle, and end. Young people, new to grief experiences and enmeshed in an "instant" society, are ill prepared for the devastating pain and loneliness of loss and for the tasks of mourning that need to be accomplished before healthy resolution can occur.

The experienced practitioners in a hospice program, where grief in all its manifestations is recognized and acknowledged, can play a significant role in the lives of the various "hidden grievers." Hospice staff working through the grief process with the bereaved either on a one-to-one basis or in a group setting, find that those grieving often discover that working through grief, despite its terrible pain, can become a significant factor

in individual growth and development. Many reach new depths of humane and spirituality when they are assisted in their grief work to accomplish the tasks of mourning. Lastly, we look at the grief of those who have been the hospice caregivers in the hospital, the clinic, or at home.

The Caregiver

The term "hidden grievers" encompasses another group of individuals of whose grief others have little awareness. They are the hospice nurses, physicians, social workers, counselors, and volunteers who have spent much time with PWAs. Society doesn't think of professional caregivers as individuals who often experience a deep sense of loss when a patient with AIDS for whom they have cared and grown to appreciate, and even love, dies. Professionals are considered the "strong" ones, people prepared by some special curriculum to face dying and death, even if it occurs several times in a 24-hour period, with equilibrium, even detachment. The reality is that caregivers are, first and foremost, human beings who are often deeply concerned and committed to working with patients with AIDS. Frequently these caregivers have chosen to care for people with AIDS. For these caregivers, hospice care means not intensive technological care but intensive people care. With PWAs, this intensive people care is further augmented by the bonds that are created between a caregiver and patient who is confronting his or her death. Helping people with AIDS face the losses inherent in the progression of their illness means sharing intimate moments with special people. Lamme (1984) wrote that "anguish is always present when we are forced to say goodbye" (p. 33). It is present for the PWA and it is present for the caregiver.

Working with the dying and the bereaved can touch caregivers personally in several ways. Such work can reawaken pain over personal losses, increase apprehension regarding potential losses in the caregiver's own life, and perhaps bring to awareness troubling feelings about the caregiver's own mortality. Feeling helpless in the presence of a disease that always ends in death can be debilitating and depressing.

This very pain of grief, however, can contain for the caregiver the potential for growth. Often it is in the midst of sorrow that we are forced to take time to assess the meaning of our

own lives, evaluate our priorities of living, and, perhaps, experience the real substance of life. Sometimes it is our grief that helps us to realize the difference between existing and living.

Implications for Caregivers

AIDS patients, unlike any other patients we have encountered, are generally aware that their illness has no cure at present and will ultimately end in death. One must be aware that patients slip in and out of denial about their illness, about whether they will "beat the odds." Gentleness is needed when the patient seeks comfort for a brief while in self-deception. One must not push toward reality. A physician, for example, who thought it best to lay forth to the patient the new results of some diagnostic work told him that what he had was an overwhelming cryptococcal infection and that his life expectancy was now 4 weeks. The nurse came upon the patient shortly after this disclosure and found a young man struggling to hold himself together. While she was there, an intern who came in to draw his blood said, upon leaving the room, that he would be back in 10 minutes to answer some questions the patient had. In fury the patient screamed, "Do you know how long 10 minutes is for someone who has only 4 weeks?"

In working with these patients, one must be alert to the issues that surround dying and death—the need to say goodbyes, to tidy up one's affairs, to reflect on one's life, and to come to terms with how that life has been. The caregiver must be comfortable with confronting these issues with the patient. The patient is not looking for answers for the most part but, rather, is looking to be heard, to have someone tolerate the expressions of fear, anxiety, and pain concerning what he or she is about to lose. It is the honest responses, the willingness to explore the ending of a life as one does the beginning or middle that makes it possible for the patient to relinquish his or her anxieties and move toward a peaceful closure in life. Moving a person toward that peace is the most caring, the most loving approach that one human being can offer another.

Conclusion

Not every person with AIDS will elect hospice services nor is hospice care advocated for all people with AIDS. Our hope

is that the reader will be able to appreciate that hospice care is a viable option for PWAs and that many such persons and their loved ones have benefited and will continue to benefit from its philosophy and how it is played out in relation to the multitude of problems and issues inherent in this dreaded illness. In Rossman (1979), Edmund Pellegrino, M.D., Director of the Kennedy Institute of Ethics, summarizes the value of the hospice concept and philosophy to all terminally ill persons in the following words:

> The challenges for medical, nursing and health profession educators are direct, specific and inescapable as they are for administrators, boards of trustees and public policy makers. The ideal of patient-oriented, patient-centered, and patient-directed medical care is, perhaps, the most difficult unmet challenge before us today. . . . the hospice movement alerts all of us to a signal deficiency which no amount of elaborate technology, systems organization, or managerial efficiency can obliterate. Only persons can care, and without caring even the hospice idea becomes just another formula. (p. 8)

References

Anderson, H., & MacEnroe-Boehm, L. (1988). End of life with AIDS: New challenges for hospice programs. *Live Hospice Journal, 4*, 37–41.

Expert Working Group on Integrative Palliative Care for Persons with AIDS. (1988, Dec.). *AIDS and ... Basic approach and resource kit for the terminally ill person: AIDS plus* [condensation of *Living Together*, report to Health and Welfare Canada]. p. 16.

Filson, C. R., & Lanzafia, C. R. (1988). Psychobiological and the AIDS outpatient. *Focus: A Guide to AIDS Research, 3*, 2.

Gantz, V. J. (1987, Fall). The positive aspected diagnosis. *American Journal of Hospice Care*, pp. 35–43.

Marzuk, P. M., Tierney, H., & Tardiff, K. (1988). Increased risk of suicide in persons with AIDS. *The Journal of the American Medical Association, 259*, 1333–1337.

Rossman, P. (1979). *Hospice*. Pearl Jersey, NJ: New Century Publishers.

Saunders, C. (1967). Words and pain. *Nursing Times, 63*, 1643.

Chapter 11

SUSTAINING THE SPIRIT

Rev. Albert J. Ogle

Jim Cotter, a theologian from England, described the ancient and still practiced custom of building "cairns" with stone on lonely mountain paths to mark some special, significant places (1987). People would merely add a stone to the existing pile as they journeyed on the way to the next marker in search of the journey's end. There is comfort and hope in the knowledge that other human beings, bewildered, tired, challenged, and caring have gone this way before; the "cairn" represents something of a collective consciousness and solidarity with fellow travelers. AIDS presents counselors with an opportunity to contribute to the existing markers on the paths from birth to death. When the AIDS crisis is over, which stories or memorials will remain? What can be learned from those who have died? This chapter shares experiences, ideas, and strategies for counselors and their clients when looking at spiritual issues that emerge as part of the AIDS crisis.

AIDS: A Crisis for the Counselor

One of the most powerful feelings associated with AIDS is isolation. Legislation, special health care programs, and attitudes in society either isolate the person with AIDS or integrate him or her. This is also done to people in leadership positions in health and psychosocial care of AIDS patients, for example, counselors. Counselors need to ask, "Am I feeling isolated in my AIDS work or integrated?" Counselors will only be really effective as they integrate themselves and their clients into a

"family-like" model that is truly our natural *support system*. Rabbi Edwin Friedman's book *Generation to Generation* (1985), although basically a handbook for pastors of congregations, gives a useful approach in how to work with crisis situations in families and congregations utilizing a family systems model. This model can also help counselors and therapists be effective in their work and avoid burnout.

Friedman's (1985) basic thesis is that as a community "healer," a counselor cannot isolate a family, congregational, or client's crisis from his or her own interior work. Counselors must contemplate why they are working with AIDS patients. What issues in their own life and value system surface for them as a result of AIDS? It may be that the counselor is gay, that the counselor identifies with younger people suffering and dying, that the counselor has lost a close friend or family member, or that the counselor feels a moral imperative to "do" something. Whatever has "dragged" counselors into the AIDS experience needs to be owned and clearly defined if counselors are to be effective. Friedman uses the term "self-differentiation" to describe the need to own one's own issues and differentiate from the external crisis. If the congregational leader or counselor isn't aware of his or her own direction, goals, or motives, there is little hope that the counselor will be of much use in helping a person with AIDS, a family, or a community understand or love themselves more fully.

The personal challenge to all people engaged in AIDS-related work is how to balance professional and personal "self-differentiation" with owning one's issues that are stimulated by people with HIV and AIDS. There is much work for counselors to do with people who come to them for help and meaning in their lives, and their process often stimulates the counselors' own. Counselors can be effective only in as much as they recognize and develop their own growth. The mental health profession is having to face deep dark questions that are, in essence, profoundly spiritual. For example, the chapter's author recently conducted an inservice training on AIDS for special education teachers in Los Angeles. It was difficult work, highly demanding, low paying, and not significantly recognized by the community at large. It was engaging for the author to relate his experience of working with persons with AIDS with working with their population. They had chosen to involve themselves deeply with members of society who have been ostracized and largely ignored, and yet they loved their work and the people

they served. "Vocation" is a word that is intimately connected to the word "profession." To profess is to *believe* that you want to and are skilled enough to do a particular job. For many people in health care professions particularly, AIDS is providing an opportunity to evaluate their motives and skills to do rigorous and demanding work. In looking at our motive and vocation, we find a way to work through our fears and frustrations. If health care professionals cannot find a balance, they might need to reconsider their careers and career goals.

Breaking Isolation

No profession is immune from the profoundly existential questions posed by the child with HIV infection, the employee who has AIDS, the legal and political implications of sound public health, and the battle against hysteria and homophobia. Even those counselors or clergy who have given their lives to serving those with AIDS must constantly review where they are. Counselors working with people with AIDS must continually question themselves. "Can I take on another client who is showing symptoms? Do I want to end up with a totally AIDS-affected client population?"

Sometimes counselors will despair and get angry as they lose friends and clients. The author recently spoke to a man in his late 30s, involved most of his life in human services, who was now caring for a man with AIDS in his own home. Painfully he told of how he moved into his new home several months earlier. "I had to move house on my own with no one to assist me because all of my friends are gone now." There is something profoundly tragic about a 30-year-old man left friendless because those close to him have died of AIDS. The same "abandoned" look could be seen on the face of 70- and 80-year-olds in warehouse-like geriatric homes in Ireland. All their contemporaries had gone and they were merely waiting their turn to die. Counselors can learn much form the collective experience of seniors who have lost spouses after many years of relationship. As the extended family disintegrates in cities all across the Western world and an ageist culture does all it can to deny aging, there is an amazing resource in the elderly, neighbors, family, or members of religious congregations who *know* what many people affected by AIDS are going through.

Friedman's "family model" can be helpful to clergy and counselors seeking to build a support system for their clients and themselves. The family model has been a great resource in the parish of All Saints Church in Pasadena, California. Some of the greatest supporters of AIDS work at All Saints Church are a group called "Senior Saints" who get together for a potluck each week. The unfortunate ghettoization of gay versus straight and young versus old can often be healed in places like a religious congregation. The parish church or synagogue may be the *only* place left in society where this intergenerational diversity can take place. Without this connection to a community of seniors, children, expectant mothers and others, where life and death are both embraced and expressed, counseling would be meaningless. This integration is life-giving to all involved. For people with AIDS, the grieving, and the worried well, this represents a "whole" community in which healing, communication, support and dying well can take place.

An Emerging Family Consciousness

It was only 60 years ago that millions of people in Western Europe were wiped out by a great flu epidemic. That painful collective consciousness is still alive in those who remember and in the legacy of community response. For example, in 1933 the author's grandmother gave birth to his father and named him after a 14-year-old boy who died in that epidemic. The boy's mother had helped with the author's father's birth at a time long before maternity wards existed. When the author was born, he was given the same name as his father.

The legacy of community response still exists today, though perhaps under the surface. Counselors have only to ask or reflect, and in doing so can discover a community consciousness and collective expressions of loss and grief. In every village in Ireland and England memorials have been erected with names of young men in their late teens and 20s who were killed in the battlefields of France during what is euphemistically called the "Great War." Even those who did not live in America during the Vietnam War weep at the Vietnam Memorial with its half-emerged list of names in black granite. Looking a certain way at those lists of names one can see one's own reflection in the painful memorial—its half-covered position in the Washington

earth reflecting American consciousness over a tragedy that is still not fully owned or grieved.

In 1988, most cities in the United States contributed panels of cloth, like quilts, that carried the names and personal stories of people who had died from AIDS. These panels were often made by lovers, friends, and family members. The Names Project Quilt is a significant contribution to the struggle with community consciousness. It is a way of grieving and sacramentalizing (offering an outward visible sign of an inward spiritual experience) the AIDS crisis. This was profoundly felt during the 1988 Episcopal Church's General Convention in Detroit that coincided with a 2-day visit of the Quilt. Some of the members of the board of the National Episcopal AIDS Coalition had worked hard to ensure a booth at the convention that would educate, advocate, and develop compassion in our congregations. There was excellent media coverage and nine excellent AIDS-related resolutions passed both legislative houses. However, it was a simple ceremony of dedicating three new Episcopal AIDS panels to add to the existing 11,000 panels that really touched people deeply. Midwesterners, WASPS, bishops and a cross-section of the American public were visibly moved by what they saw on the stony quiet floor of the Convention Center. Many editorials and after-convention reviews reflected the impact the AIDS quilt seemed to have made, burning itself into the very hearts of a significant section of the community that will never be the same. The presiding bishop, Edmund Browning, was heard to say privately after the ceremony, "This is the most significant thing I have done here." The quilt is a modern day cairn.

In Los Angeles, in the past 3 years, community consciousness has been helped through the organization of 10 specific liturgies called "AIDS masses." These masses encompass a Eucharist with an AIDS-related homily, special prayers and readings for healing and courage, and a remembrance of those who have died. They occur almost every 3 months in parishes all over the diocese with eight being celebrated by the bishop of the diocese. The local Catholic archbishop also presided at an AIDS mass and was visibly affected by a 3,000 strong congregation of mainly gay Catholics and their friends. The AIDS masses also recognize significant individuals in local communities who have shown personal leadership and courage in medical, spiritual, educational, and political strategies in dealing with AIDS. The masses help people to grieve, to center them-

selves in the important community values of care, compassion, and solidarity, and to offer to God the people they love, miss, and hurt for, as well as their own fears. In the beginning when AIDS was still highly stigmatized (the days before Rock Hudson was diagnosed) the masses attracted massive media attention. To have a bishop saying mass in a church for AIDS was controversial and highly political. In those parishes that had the courage to sponsor an AIDS mass, there has been a renewed commitment to the ministry of healing of the church in caring for the sick, their families, and caregivers. There is also a new dialogue between the church and the gay and lesbian community. In retrospect, the AIDS masses' most significant contribution has been the renewal of commitment by several key parishes in Los Angeles Diocese to minister to and with gay and lesbian people. More significant, and perhaps surprising, is that many of the heterosexual parish members *wanted* to be involved in this ministry.

AIDS at the Parish Level

In All Saints in Pasadena, California, the AIDS Mass in 1986 led to the creation of the All Saints AIDS Service Center that is currently the principal AIDS-related mental health and case management project for California's Western San Gabriel Valley, employing 12 full-time staff and 250 volunteers. The parish community of the past 20 years has greatly contributed to various social health and peace and justice issues, so working with AIDS was seen as a natural profession of a concern for the welfare of the local community and advocating for the oppressed while healing the sick. All Saints staff has been careful not to develop AIDS programs that are overtly religious or exclude people on religious grounds, with the AIDS-affected community largely unchurched and largely damaged by religious and secular homophobia.

There are several parish programs other than the AIDS program that meet the spiritual needs of the client population. People are encouraged to integrate into programs like Bible studies, discussion groups, and worship services rather than to duplicate them. Gay and lesbian people are welcomed at this parish and an active gay and lesbian support group [Gays and Lesbians All Saints (GALAS)] has been providing spiritual and

social programs for the last 5 years. It has been important to separate the issue of homosexuality from the issue of AIDS ministry. The AIDS ministry has been successful because the parish community is already aware and working on its homophobia and is committed to diversity within the congregation. Inservice training programs for staff and informational programs on gay and lesbian people as well as active participation and leadership of gay and lesbian people have helped raise consciousness in the congregation. It would be impossible to provide the trust and honesty needed for a strong and safe pastoral and community relationship with a gay person with AIDS without a congregation working through its homophobia and issues around sexuality and diversity. Congregations that are largely White and homogeneous are usually unlikely to welcome gay people or minorities and may patronize or proselytize persons with AIDS or the worried well. The various "change ministries" like Exodus International and some Catholic attempts at ministry to the gay community have deep philosophical and theological problems with honestly nurturing gay and lesbian people. Heterosexual members of the All Saints staff are reminded that every time a gay man or woman comes to church, he or she is coming back to the place where they first heard that their "love is not good" and that they themselves were unlovable.

Religious homophobia is a frighteningly destructive phenomenon that often kills people spiritually and sometimes even leads to physical death. For example, one of the author's closest friends, Frank, who died from AIDS, confessed from his darkest self-loathing as a gay man that he wanted to die from AIDS. Somewhere inside his heart he had picked up a wrong message about himself that he carried with him most of his life. In the last 2 weeks of his life, while hospitalized, he was surrounded by so much love and affirmation from his friends and family that he could no longer believe bad things about himself. He died loving himself for the first time and was fortunate to have had 2 weeks to do a deep spiritual self-reappraisal.

Many religious institutions, particularly the fundamentalist wing of the church, inadvertently destroy and maim people through homophobia. It is often forgotten that the crucifiers of Jesus and the murderers of the prophets were deeply devout religious people who wanted to maintain the status quo and thought they were doing God's will. The same forces are still at work in deeply devout, well meaning people who maintain

that AIDS is somehow a manifestation of God's punishment on a sexually promiscuous society or chemically addictive people.

AIDS patients and their families and friends will encounter prejudicial attitudes at some level as they interact with society. This will often stimulate early memories in individuals of a damaged self-image, usually influenced by parents, peers, religious people, teachers, and others in leadership positions. These reactions can be the window through which those early memories can be healed with the client integrating more positive values and self-image into his or her contemporary situation. Spence (1986) outlined some personal and group exercises for integration of adult reality with the negative tapes first heard as small children. One of the exercises involves two people facing each other. The listener holds the other person in complete respect and positive regard without any form of criticism or negativity. As the other person recalls painful or disempowering situations, emotions of inadequacy, failure, a lack of skill, intelligence, sexual attraction, a sense of isolation, or withdrawal of love and support may emerge. As adults we can look at the old hurts and, with the partner's help, own our true sense of goodness and self-worth as they tell us what they see. The process of recognizing the inherent worth of a human being fraught with negativity is illustrated in the following case example.

> In the summer of 1988, one of the board members at All Saints who is a person with AIDS was in the hospital for the amputation of his right leg. The day following the amputation, he was in great pain and needed medication. In the midst of all this a homophobic religious nurse told him she hoped he knew that God loved him because AIDS had obviously resulted from his gay life style that was against God's will. She did not say, "AIDS is a punishment from God for your gayness," but it was certainly communicated that he was living immorally and punishment for self-destructive behavior was inevitable. Armando was very gracious to her, took the opportunity to give her some AIDS and theological education, and made a formal complaint to the hospital. The effect of all this on his spirit, however, was enormous. He was from a Catholic Hispanic background and the nurse stirred up all of his negative self-image issues. The next day, Armando had regressed, vomiting with help of and the living

on of hands, a traditional Christian symbol for healing and love. Six of his closest friends and the author used this opportunity to surround Armando symbolically with the reality of his goodness as a gay man and the reality that he was incredibly loved by those present and by God. We stood around his bed, acknowledging that what happened to him was painful and emotionally draining. We affirmed what we loved about him. Many of his friends spontaneously shared their love for him with humor and deep emotion, during which he closed his eyes, relaxed, and breathed deeply. We used guided imagery of "a healing sphere of light" entering his body and his heart. We also touched him and anointed him with the holy oil. We all participated in the experience. As a priest I was supported in my ministering to Armando by a community of his friends. Armando smiled deeply and shared how loved he felt. Within 3 weeks he was out of the hospital and made a remarkable recovery from his surgery.

The love and reality of healthy relationships penetrate the deep dark places of self-loathing and self-hatred. This can be facilitated by community experiences like the one described. At the AIDS Service Center one of the 10 support groups specializes in guided imagery, meditation, acupressure, massage, and touching. This seems to be an important therapeutic support system for some of the clients and staff. It operates in conjunction with more traditional psychosocial programs, many of them facilitated by a mental health professional. On a weekly basis there is a small intimate worship group that celebrates the Eucharist together and ends with the "laying on of hands." This is a traditional demonstration of solidarity with the sick or suffering where a priest or group of worshipers lay their hands on the head, shoulders, or body of a person who is seeking some form of comfort, healing, or release from pain or anxiety. The physical touching is usually accompanied by an oral prayer on behalf of the person for healing. This traditional liturgical form has proven to be a therapeutic approach for some of the AIDS-affected population.

More contemporary "alternative" or "new age" therapies also have been successfully utilized by the AIDS-affected community. However, some patterns have emerged and some philosophical or theological areas should be avoided. Some "new age"

theories include the idea that sickness is caused by a subconscious decision to sabotage or not to accept "health" as the rightful human experience. This translates into the notion that "I can choose if I want to be sick or healthy. If I have AIDS and am sick, it must be my fault. I must have done something wrong or I am just not meditating or believing in myself enough. If I want these problems to go away, I have control and responsibility for it all." Death is also seen as a conscious choice where people "leave the planet" (to use a new-age euphemism) after completing their spiritual work in the body. The danger with this approach is that it can end up reinforcing denial in the AIDS-affected community or making individuals feel that they have completely failed in life and health.

There are three positive aspects to healthy spirituality that can be integrated with modern psychological approaches to healing. First, communities most oppressed or marginalized can heal negative self-images through the positive reinforcement of their love, integrity, worth, talent and spirituality. Initially, healers often have to *exaggerate* the reality of oppressed people's goodness and lovableness so that it finally penetrates and overpowers the negative messages they learned as children. This can often be structured in group work or in individual counseling sessions.

Secondly, touching is healing. There is an almost universal feeling of being dirty or untouchable that many people with HIV feel. Being touched by another — a holding of hands or hug or more liturgical forms of touching — are all necessary for spiritual and emotional healing and growth in this crisis. When healers do not know the ailing person very well, it is often helpful to them to ask permission to hold or touch them. Close friends can hold too, particularly when someone feels "untouchable" or "unlovable." It can also be healing just to be held while talking or crying. Physical demonstrations of caring and loving can counter the oppression and negative energies people with AIDS feel. Although this may sound strange to some therapists, it has been this author's experience in working with people with AIDS that expressing intimacy physically is very important. Many local AIDS organizations train volunteers in massage and other forms of physical contact with persons with AIDS. This is an important service to people who, as a group, are often isolated and left untouched by society's fear of contagion.

Developing People's Innate Spirituality

It took 2 years at the AIDS Service Center to help clients relax around the spiritual aspects of AIDS. This is partly a reaction by gay men to their homophobic experience of traditional churches and the subsequent denial of their inherent spirituality. Churches have traditionally portrayed gay people as immoral and sinful and have greatly misused biblical quotations like the Sodom and Gomorrah story to denounce homosexuality. Some churches have refused membership and ordination to gay people, and many gay people still regard the church as the source of most of society's homophobia and prejudice against them (see Boswell, 1980). Monica Furlong (1976) sees a direct link between this suffering and spirituality. She writes in her book, *Traveling In*:

> The people whom I have loved best have all known some experience akin to this. One of them stammered, two experienced severe maternal deprivation, two were homosexual, one was seriously rejected and bullied by his peers. What made them special was not the original wound, but the fact that it seemed to open a door, which in others remained closed, a door which led into a landscape of joy. This does not happen automatically as a result of injury—people can be injured, yet remain unaware—but I know of no one who seems able to talk of this landscape without having known the pain first. (p. 26)

John Fortunato's excellent book, *AIDS—The Spiritual Dimension* (1987) further develops a theological and pragmatic approach for gay and lesbian people. He states that the gay community's spiritual wealth has to be shared at this time with their heterosexual brothers and sisters, particularly to help them process a more honest and appropriate theology of sexuality, sensuality, love, and death. AIDS will finally help the gay community and others get over their sophisticated "denial" around death.

> Most everyone would agree that it could not have come at a worse time. Here we had almost succeeded in obliterating death from our consciousness. We had

worked so hard for so long. More than a century of progressively hiding the Grim Reaper, or euphemizing death, of phoneying up corpses, of putting fake grass around the hole and leaving before the box was lowered. And we were within a hair's breath of our goal (p. 93).

There is a direct connection between this "suffering community" and spiritual formation and development. Articulating these experiences of "exile" and "calling" is important if spiritual people are to somehow make sense of their lives and loss. This experience, when articulated through writing, poetry, and art, can break down the denial and externalize the pain, grief, anger, and suffering associated with AIDS. Creativity in general may be the key to the question, "How do we survive multiple losses in our lives?" This articulation is itself profoundly spiritual and theological, reflecting our journey and moving us along at the same time. For the past year, the All Saints AIDS Service Center has been producing a 20-page journal entitled *Telespuo*, named after the Greek god of healing. It is a window to the AIDS experience for its 2,000 readers each month. It has helped people share their stories, articulate their varied experiences, and show solidarity with one another as a caring community, as seen in the following excerpts.

YOU'VE HELPED US COPE

Contributed by Jim Goodwin, a member of the AIDS support group.

My wife and I were caregivers for our son, John, during his fight with the AIDS virus and all of the opportunistic diseases to which he was susceptible. All Saints AIDS Service Center provided us with a lot of information. We found that listening to other PWAs' experiences with drugs and medical treatment made it much easier for us to participate with our son and his medical team. It made us knowledgeable enough to the point where the medical team used us to determine reactions to medication; we kept track of time, amounts, nausea, diarrhea, fever spikes, and mental state. In return, the medical team kept us informed on PCP, MAI, various fungal problems, and KS, plus the purpose of tests and the validity of test results.

We've used information we received from so many people at AS/ASC to fight fevers, stop diarrhea, whet our son's appetite, and do a lot of practical things that helped John's quality of life that we don't remember whom to personally thank. All we can say is we love you all. But there was a lot more than the practical things that we acquired from AS/ASC; it had to do with our emotional states. Some of the emotional problems were not directly connected to AIDS, but were a by-product. How does an adult who has been financially devastated cope with returning to live with his parents? How do the parents cope with the emotions of the returning adult son? What we, and I mean the whole family, found was that discussing these problems at AS/ASC group meetings somehow led us to an acceptance that made it a lot easier to cope when all parties had been able to get to the root reasons for the anger, frustration, and feelings of losing control. We don't mean the problems were solved; it's just that we learned to cope with them. It wasn't unusual to come to the group an emotional mess and leave feeling like that 600-pound gorilla was off our back.

The result of our relationship with AS/ASC has been that the last months of John's life were filled with beautiful moments that the family will always cherish. If left on our own we never would have progressed in time through the initial trauma stages to arrive at acceptance and to have enjoyed so much the time we had together. If our son hadn't had AIDS and we all had been able to live lives of the normal span of years, we wouldn't have known each other any better or loved each other more than we do now. This brings us to another aspect of our relationship with AS/ASC: we want to pass on to other caretakers and PWAs the message that when AIDS enters a family the experience isn't all bad. What seems to be required is to work through the problems as quickly as possible and enjoy your new, deeper relationship with your loved one.

JUNE 22, 1988

Last night I dreamed
about telling my father I have ARC.

I was scared, as I usually am
in my recurrent "I'm dying of AIDS" dreams.
Upon waking up, I slowly remembered
that I don't have AIDS.
I'm not even HIV-positive (I don't think).

So why do I have these nightmares?
What am I afraid of?
I'm one of the lucky ones.
Aren't I?
But

Will I die of old age, impoverished and alone?
Will I be tortured, raped, or murdered?
Will my life be snuffed out in a car crash?
Will I get cancer? ALS? Muscular dystrophy?

I've always "known" I'm going to die.
But I never really believed it
until my friends came down with AIDS.
Is it comforting to know what you're going to die of?
The unknowns about my own dying are beginning
to terrify me.

—*Lee Brown*

Dixieland

"Well, I wish I was in Dixie..."
isn't that a song?
"Look away, look away..."
same song?
"... and die in Dixie"
wrong tune

You died in your bed
with flannel sheets and
six pillows.
With a black down comforter
and blue pajama tops.
You were propped up
like the little boy who died
in a book of bible stories
my pediatrician had in her office.

You had morphine going into your veins
and tortured, ragged breaths

leaving your body.
You had a raging fever
that glistened as beads of sweat
on your forehead.
You had my tears splashing on your hand
and your fingers failed to grasp mine in return.

I died in your bed
with flannel sheets and
six pillows.
With a black down comforter
and tears that lodged in my throat
no matter how furiously they flowed.

"Old times there are not forgotten,"
still that song:
"Look away, look away, look away
Well, let's finish it—
"Dixieland."

—*Melinda A. Welch*

Homecomming

Dedicated to my son John
January 1956–April 1988

Son you have come home
You are not seeking promises,
all you want is my love.

You know well
what I have deep in my heart,
only love and my labor for you.

You need my hands,
my weariness, that you may rest,
and a love that can continue to love.

Son, you have looked into my eyes
Smiling, you pronounce my name
You shall find peace
amidst those who eagerly wait.

I have left you to go into the sky.
Now I am lost in my cry,
I am your mother, your friend.

Your love will last forever,
your faithfulness is as permanent as heaven.
With you at my side
I shall seek another day.

—*Carmen Gaudiano*

Encouraging people to write about what they are going through and having it published is a wonderfully powerful way for the AIDS-affected community to reflect and experience their calling. It counters the tremendously debilitating feelings of powerlessness that people with HIV infection feel.

Making People Feel Clean and Loved Through Traditional Symbols

Feelings of being "dirty" that often link disease, sexuality, and racism are inherently spiritual in nature. Dr. William Countryman's book *Dirt, Greed and Sex* (1988) links sexuality and disease with the biblical concept of "purity." AIDS is a purity issue. These concepts are spiritual and theological and cannot be tackled only on an intellectual or behavioral plane. The Jewish and Christian scriptures attest to the importance of healthy eating, drinking, sexual, and social practices that were either ritualized or were developed into laws. The Jewish laws ritualized good dietary practices of a people intent on survival. Those who did not follow these laws were "unclean" or "dirty" and were to be avoided outside the tribe or society. These attitudes profoundly influenced Christianity, which still regards creation as inherently sinful, fallen, and dirty. Baptism with water is the ritual that symbolically makes people "clean" and "good."

Touching and symbolically washing can be helpful antidotes to this debilitating stigma. Many people with AIDS have been baptized as Christians, and a theological understanding of this "rite of initiation" could be a great source of healing and empowerment. The more traditional usage of blessing oneself with holy water on entering or leaving a church or a blessing of a liturgical gathering with holy water is also a physical manifestation of cleanliness as God's people. On Maundy Thursday there is the symbolic representation of love and servanthood at the traditional washing of feet, enacting Jesus' washing of his disciples' feet. The author knows of no greater symbol of intimacy apart from sexual intercourse that describes love and

nurturing than washing, anointing, and massaging someone's feet, as the following personal example illustrates:

> When Frank was dying in London, both of us found it difficult to share our feelings about what was happening. I wanted to celebrate the Eucharist with him—liturgically sharing the broken bread and cup of wine, symbolizing the feast and the experience of suffering. I wanted a symbol or vehicle to express our connectedness and love. Frank wasn't particularly religious and it was, therefore, not appropriate for us to do the Eucharist together. In the middle of a pedicure, however, I reached for some oil and began to massage his feet, which he thoroughly enjoyed. Between the words and polite talk something more profound was expressed. He *knew* what I was doing. It was a sort of preparation for burial, a "safe" symbol, a moment of intimacy as friend and priest. It was an important part of our rituals of closure and celebration of our lives together. The action was more powerful than anything we might have spoken. Later, we would use other symbols to say goodbye. In his final conscious moments Frank was unable to speak because of the life support system. Through a "speaker board" he pointed to letters that spelled out "I loved rediscovering you and I always will." The power of those letters, those symbols, are with me forever.

Helping people use their symbols and traditions at moments when words seem inappropriate is a wonderful gift. It can facilitate healing at our deepest level and can express our common solidarity. It is the author's belief that this is the greatest contribution the religious and spiritual community brings to the AIDS crisis.

As AIDS moves into the Hispanic and Black communities, the spiritual dimension of AIDS will only be heightened. These two historically oppressed communities have found solace and empowerment from Christianity, which ironically was also used to oppress them. The model described for the gay community of working through its negative self-image, self-oppression, and self-destructive behaviors can be applied to these communities. There are obvious sexual stigmas and fixed attitudes, particularly to homosexuality, that need to be worked through in both communities. Working with families and church-extended fam-

ilies may be easier in these communities where family values are still strong and the extended family still seems intact. Research done to set up an All Saints Spanish-speaking support group found that a woman psychologist or priest provided the most accepted and comfortable leadership for this group. The woman or priest is seen as a nurturer and protector of the vulnerable. Here again, spiritual values and metaphors will help counselors and clergy integrate AIDS within communities who are having a difficult time with prevention and education. The religious community, particularly the Black gospel churches and the Roman Catholic and charismatic churches in the Hispanic tradition have a major role to play in preventing the spread of the disease and organizing the local community to care for the sick and grieving. Professional relationships with clergy and leading laity by psychologists and others engaged in AIDS ministry should be of the highest priority as they prepare for future changes in the AIDS-affected population. Most cities in the United States have active AIDS interfaith councils or task forces that can provide many resources at a local level and often a great deal of "moral clout" when it comes to defeating unhealthy legislation, mobilizing a community for particular projects, or promoting AIDS awareness programs. Ironically, the religious community often holds the keys to both future problems and future solutions in any community. The Roman Catholic Church could be the most powerful institution in the United States for AIDS prevention (particularly among Hispanics) if it advocated the use of condoms for prevention of AIDS. The church, in calling for a moral consciousness and compassion for people who are ill, has done more than any community organization in pushing mental health care providers, politicians, and the general public into the more acceptable "integrationist" position for persons with AIDS rather than the isolationist position.

It will be important for counselors to try to understand the part played by spiritual formation in the lives of their clients. For many gay people, the church, a common vehicle for spiritual formation, has been hostile and a bastion of oppression. In rejecting the church, many gay people feel alienated or without a "family" or reference point. Those who go into "new age" religions can often reinforce those earlier spiritual images of guilt and failure, or instead can break into new levels of consciousness with improved self-esteem, self-worth, and social integration.

In the "life and death" situation of AIDS, profound questions force all people involved to look for meaning and points of reference in their experiences and be more introspective and reflective. A healthy spirituality can help people through difficult decision-making processes, and a spiritual support group can give people social support and intimacy at a time when they may feel terribly inadequate, frightened, and alone.

Conclusion

During the last 4 years of full-time AIDS ministry, the author has worked with the patients, families, congregations, minorities, health care providers, psychologists, clergy, business leaders, politicians, and the man and woman in the street. Maintaining his sanity and sense of meaning in this "warlike holocaust world" has required deeply personal, spiritual "well-drilling," or suffering the consequences. In these 4 years the author has been closely associated with spiritual people and has constantly used them as a sounding board for his own reflections, anger, and insights as he sought to interpret and integrate these experiences into his own life. This has recently been formalized through a monthly weekend support group of three people, all involved with AIDS-related work and members of All Saints parish going on retreat outside of Los Angeles. There they eat, laugh, cry, share Eucharist, write journals, read, and renew and love each other through some moments to themselves. This support system has been an invaluable spiritual source and breaks the sense of isolation that many feel.

Each counselor who commits to the "long haul" will need to develop safe spaces for him- or herself, carved out of the pain and tragedy and sheer weariness of the AIDS crisis. It will be at places like this that they will be able to share their deepest fears, move beyond their own inner limitations, and be nurtured through the crisis. Through AIDS-related support groups and parish congregations, counselors can attempt to create an intergenerational diverse family to absorb some of the pain of AIDS. In doing so, counselors will help to integrate rather than isolate.

References

Bozarth, J. (1984). *Uncommon sense and common nonsense*. Chicago: University of Chicago Press.

Countryman, W. (1988). *Dirt, greed and sex*. Philadelphia: Fortress Press.
Cotter, J. (1987). *The casino network*. Exeter: Cairns Publications.
Fortunato, J. (1987). *AIDS: The spiritual dilemma*. San Francisco: Harper & Row.
Friedman, E. (1987). *Generation to generation*. New York: Guilford Press.
Furlong, M. (1970). *Traveling on*. London: Hodder and Stoughton.

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